A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

Robyn Carol Williams

Thesis presented in fulfilment for the degree of Master of Arts and Social Sciences in the faculty of Psychology at the University of Stellenbosch

Supervisor: Dr. R. Roomaney

Co-supervisor: Prof. H. Simonds

December 2020

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: 02 September 2020

ABSTRACT

The high prevalence and burden of cervical cancer in developing countries has spurred on much research into preventing and screening for the disease. However, little research has focussed on the experience of living with the disease and undergoing treatment for it in South Africa. This study sought to collect in-depth accounts relating to women's psychosocial experiences during the trajectory of cervical cancer.

The researcher conducted semi-structured interviews with 15 women who had completed curative treatment for cervical cancer at Tygerberg Hospital, Cape Town, to gather information relating to their experiences. The researcher formulated questions considering the main objectives of the study, which were aimed at exploring the knowledge and awareness of women with regards to cervical cancer and how this changed during their experience, their psychosocial experiences at the time of diagnosis and during the course of treatment, and how their subjective-wellbeing was influenced. Interviews were analysed with the application of the principles of thematic analysis, and the arising themes were then conceptualised with the use of the Illness Intrusiveness Theoretical Framework.

The results of this study indicated that women experienced both treatment and disease factors which interacted to influence their daily lives and subjective well-being. Limited knowledge pertaining to the cervical cancer was reported, yet women gained insight into their condition throughout the trajectory of the disease by interacting and communicating with healthcare providers and other women who shared similar experiences. Such communications played an important role in dispelling the misinformation and stigmatising ideas that women reported encountering, which had influenced their attitudes in response to their prognosis and their decision of whether to disclose their diagnosis. Supportive interpersonal relationships with partners and older children also emerged as important. These reported factors and experiences ultimately interacted to influence women's subjective well-being.

OPSOMMING

Die hoë voorkoms en las van servikale kanker in ontwikkelende lande het gelei tot baie navorsing om die siekte te voorkom en te ondersoek. Min navorsing het egter gefokus op die ervaring om met die siekte saam te leef en in Suid-Afrika daarvoor te behandel. Hierdie studie het gepoog om diepgaande verslae te versamel rakende vroue se psigososiale ervarings tydens die trajek van servikale kanker.

Die navorser het semi-gestruktureerde onderhoude gevoer met 15 vroue wat genesende behandeling vir servikale kanker in Tygerberg-hospitaal, Kaapstad, voltooi het om inligting oor hul ervarings in te samel. Die navorser het vrae geformuleer met inagneming van die hoofdoelstellings van die studie, wat daarop gemik was om die kennis en bewustheid van vroue met betrekking tot servikale kanker te ondersoek en hoe dit tydens hul ervaring verander het, hul psigososiale ervarings tydens die diagnose en tydens die behandeling, en hoe hul subjektiewe welstand beïnvloed is. Onderhoude is geanaliseer met die toepassing van die beginsels van tematiese analise, en die opkomende temas is daarna gekonseptualiseer met die gebruik van die Teoretiese Raamwerk vir Siekte-indringendheid.

Die resultate van hierdie studie het aangedui dat vroue sowel behandelings- as siektefaktore ervaar wat 'n invloed gehad het op hul daaglikse lewe en subjektiewe welsyn. Daar is beperkte kennis rakende servikale kanker gerapporteer, maar tog het vroue insig gekry in hul toestand gedurende die trajek van die siekte deur interaksie en kommunikasie met gesondheidsorgverskaffers en ander vroue wat soortgelyke ervarings gedeel het. Sulke kommunikasie het 'n belangrike rol gespeel in die verdryf van die verkeerde inligting en die stigmatiserende idees wat vroue gerapporteer het, wat hul houding beïnvloed het in reaksie op hul voorspelling en hul besluit om hul diagnose bekend te maak. Ondersteunende interpersoonlike verhoudings met vennote en ouer kinders het ook as belangrik na vore gekom. Hierdie gerapporteerde faktore en ervarings het uiteindelik saam gewerk om die subjektiewe welstand van vroue te beïnvloed.

ACKNOWLEDGMENTS

Firstly, I need to show my gratitude to my supervisor, Dr Rizwana Roomaney. Thank you for pushing me when I needed to be pushed, and for being patient with me when I needed patience. I am forever grateful for your guidance and support, especially in the moments when I felt disheartened. Most of what I have learnt during my Master's is attributed to you and your enviable work ethic. Thank you for all the effort and energy that you have put into this study, and also into teaching and supervising me.

Thank you to my co-supervisor, Professor Hannah Simonds. Thank you for making the clinic at Tygerberg a warm and welcoming place where I was able to meet the women in this study. You and your team provided exceptional guidance and support which facilitated the recruitment of my participants. The positive accounts from participants with regards to the Cervical Cancer Clinic and the interactions they had with your team truly reflect the way that you, the other doctors and nurses, and the administrators supported them during their experiences. Thank you for the time you took with me and for the work you do everyday to support and care for these women.

I would like to thank the women who agreed to participate in this study. Your openness, vulnerability and willingness to be introspective during interviews gave me insight into your experiences that I otherwise would never have been able to witness. Thank you for trusting me with these private moments.

Last, but by no means least, I would like to thank the support network that I have in my family, partner and friends. Especially, thank you to my parents who have been my foundation throughout this journey. Without you, I would not be where I am. This accomplishment is as much yours as it is mine.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter 1

Introduction, Rational for the research and Research Aims

1.1 Introduction

The World Health Organisation (WHO) (2019a) reported that 569 847 women were diagnosed with cervical cancer in 2018; a significant increase from the 528 000 reported in 2011 (WHO, 2014). Women from low and middle-income countries account for the largest portion of novel diagnoses, with approximately 90% of these diagnoses being ascribed to developing countries (Cohen, Jhingram, Oaknin, & Denny, 2019). The high prevalence of cervical cancer on a global scale, as well as the resultant burden in developing countries, has prompted much research in the field of Psycho-oncology, which focuses on the psychosocial features that arise throughout the duration of cancer (Holland, 2002).

1.2 Background and Epidemiology

Cervical cancer is a slow developing cancer, and, as such, it may take a prolonged period (even years) for symptoms to become apparent (National Department of Health [NDoH], 2017; Pillay, 2002). The most commonly associated cause for cervical cancer is the Human Papillomavirus (HPV), specifically HPV strains 16 and 18 (Cohen et al., 2019; Cooper et al., 2007; Pillay, 2002), with approximately 65 to 70% of the global incidence of cervical cancer being ascribed to these two specific strains (Laubscher et al., 2015). Approximately 99% of cervical cancer incidence is attributed to HPV infection (Delany-Moretlwe et al., 2018). Stewart, Moodley, and Walter (2018) proposed several other possible contributing factors in Sub-Saharan Africa, which may contribute to the development of cervical cancer such as smoking, oral contraceptive use, infection with HIV or other sextually transmitted disease, poor genital hygiene, female circumcision, multiple sexual partners, lack of education/knowledge relating to health, and factors stemming from poor socioeconomic factors.

Cervical cancer may be detected early by microscopically investigating cells of the cervix through the utilisation of Papanicolaou tests (also known as Pap smears). Through this procedure a sample of cervix mucosa is collected, which is then screened for abnormal cell growth (Western Cape Government, 2020). The early detection of precancerous cells on the cervix can then be removed to prevent further development. As such, the early detection of precancerous lesions renders cervical cancer a nearly curable disease (Maree & Wright, 2010; Pillay, 2002). However, the high incidence of cervical cancer in developing countries suggests that early detection efforts have encountered challenges (Cooper et al., 2007; Maree, Cur, & Kaila, 2014; Mosavel, Simon, Oakar, & Meyer, 2009; Tathiah, Moodley, Denny, Moodley, & Jassat, 2014).

Cervical cancer is the second most commonly occurring cancer diagnosed in women in South Africa (Sabulei & Maree, 2019; WHO, 2019b). The latest statistics from the WHO (2019b) reported 12 983 new cases of cervix uteri cancer in South Africa in 2018, accounting for 21.7% of cancers among women. This same report indicates that 5595 deaths occurred during the same period as a result of metastatic cervical cancer. In comparison to the statistics which were available in 2010, which indicated 5 433 new cases (CANSA, 2010), a significant increase in the incidence of cervical cancer in South Africa is evident.

According to Maree and Wright (2010), the prevention and early detection of precancerous lesions is the most effective way to minimise the associated high incidence and mortality of the disease. Therefore, the majority of psycho-oncological research has focused on factors which influence prevention and screening adherence in South Africa. A lack of knowledge and understanding about the disease have proven to be barriers to the health-seeking behaviour of individuals in relation to their screening practices (De Abreu, Horsfall, & Learmonth, 2013; Maree & Wright, 2010). Uncertainty and dread of the actual screening process and Pap smears (De Abreu et al., 2013; Mosavel et al., 2009), as well as the stigma

associated with gynaecological cancers and conditions including HPV, act as barriers to women attending pap smears and treatment at a later stage. One such stigmatising idea that is commonly encountered is the assumed association between cervical cancer and promiscuous behaviour (Learmonth, Jansen van Vuuren, & De Abreu, 2015).

Several psychosocial hindrances have been identified which influence women's attendance and adherence to screening opportunities. One the other hand, research has also identified certain factors that encourage women to improve their health-seeking behaviour. De Kubber, Peters, and Soeters (2011) indicated that 52% of the women from their Eastern Cape study reported that a desire to stay healthy motivated them to attend the available cervical cancer screening programme. The hope of gaining insight into personal health matters, and the potential alleviation of cervical cancer symptoms have also been found to be motivating factors among a sample of underprivileged women in Cape Town, South Africa (De Abreu et al., 2013).

The effect of cancer on the lives of patients and how they coped with the emotional and physical changes and challenges which arose due to cervical cancer varies. Patients respond in various ways to a cervical cancer diagnosis, the treatments that they undergo and the outcomes thereof, as well as the prognosis of their cancer (Deverell & Ross, 2004). Physical, economic, occupational, social and psychological changes interact and have a resultant influence on subjective well-being. In fact, Paget (as cited in Deverall & Ross, 2004) suggested that the psychosocial factors associated with these changes may influence the outcome of cancer.

This study proposed exploring the psychosocial experiences of South African women as they undergo curative treatment for cervical cancer. It also sought to explore the effect of such experiences on patients' subjective well-being. In doing so, awareness may be raised,

which could guide healthcare providers in how to improve the treatment experience for women with cervical cancer from a psychosocial orientation.

1.3 Rationale for the Research

Despite the high incidence of cervical cancer in South Africa, limited qualitative research has been conducted or published on the psychosocial aspects of living with the disease. Previous cervical cancer research has predominantly focused on women's responses to preventative and screening strategies, barriers to health-seeking behaviour, or living with the consequences of both the disease and the various treatments that patients received. This trend is apparent in the South African context, but certain gaps within psychologically orientated research are evident. An example of such a gap is the lack of in-depth qualitative research in relation to women's experiences of curative treatment for cervical cancer and how they perceive their subjective well-being throughout the trajectory of the disease. The high burden of the cervical cancer (as typified by the number of novel diagnoses annually in the lower to middle-income populace and the high associated mortality rate) is motivation enough to focus on women who have been diagnosed with cervical cancer and have undergone treatment for the disease.

Conducting research which explores the psychosocial factors influencing a woman throughout the trajectory of cervical cancer; from her prior knowledge and attitudes about the disease to how she perceives future outcomes following treatment), has the potential to provide rich information regarding the experience of this disease. By exploring women's experiences during treatment, one is able to identify those factors which influence subjective well-being both positively and negatively. The insight gained through the study of such influences facilitates health care providers to better implement a treatment or intervention plan which tends to the specific needs of cervical cancer patients, both physically and

psychosocially, in order to advance their subjective well-being and outlook both during and after treatment.

1.4 Research Aims

The aim of the study was to explore the psychosocial experiences of women undergoing curative treatment for cervical cancer. In order to explore the psychosocial aspects influencing women undergoing curative treatment for cervical cancer objectives were developed to shape this qualitative study. These objectives involved exploring the knowledge and attitudes of women with regards to cervical cancer and how this knowledge changed from pre-diagnosis till the completion of treatment. It also sought to explore women's psychosocial experiences of their diagnosis and of curative treatments for cervical cancer and how their subjective well-being was affected.

1.5 Conclusion

This chapter served to provide context on cervical cancer, describing both the global incidence and South African prevalence and impact of the disease. I focussed on describing the risk factors associated with cervical cancer, how it may be screened for and diagnosed, and briefly mentioned potential psychosocial factors which women may encounter once diagnosed as indicated in literature. From this information the rationale for the study stems, where after the chapter is concluded with a description of the aim and relevant objectives of the study. What follows is Chapter two, comprising of both the literature review and a description of the Illness Intrusiveness Theoretical Framework, which was used to conceptualise the study. Thereafter, Chapter three addresses the research methodology, Chapter four the results, Chapter five the discussion relating to the findings and finally, Chapter six concludes the study and provides a discussion of the limitations encountered and recommendations emanating from the research.

Chapter 2
Literature Review and Theoretical Framework

2.1 Introduction

In this literature review, I discuss previous findings with regards to preventative strategies that have been implemented within the South African context, and the subsequent screening adherence practices. Thereafter the manner in which knowledge, beliefs and attitudes surrounding cervical cancer influence both the individual and social understanding of cervical cancer, health-seeking behaviour, as well as the cultural influence on these factors are addressed. The concept of stigma and the manner in which perceived life-partner support, social support, and healthcare provider interactions affects a woman's experience of the disease will also be discussed. The illness intrusiveness theoretical framework is proposed as a model to explain the interrelation of these factors and how they influence subjective well-being.

2.2 Preventative Strategies and Screening Adherence

Cervical cancer is a preventable disease, yet late presentation with symptoms is prevalent in low- to middle-income countries (Du Toit & Kidd, 2013; Maree et al., 2014). Patients within these contexts often seek treatment only once symptoms are evident; an indication of advanced disease with a poor prognosis. Attending screening opportunities prevents the majority of late diagnoses as cervical cancer can be detected during its early stages prior to the patient becoming symptomatic. Prevention and early detection of cervical cancer is the most efficient way to reduce the prevalent incidence of late presentation with symptoms and mortality rate of the disease (Maree & Wright, 2010). The goal of reducing the incidence and burden of cervical cancer has led to the majority of related research in the field of psychology focusing on preventative strategies, such as vaccination programmes, and factors influencing screening adherence in South African women. These studies were conducted to determine factors which have an impact on attitudes towards vaccination

programmes against specific strains of the human papillomavirus (HPV) (Laubscher et al., 2015), as well as screening practice adherence at primary health clinics in South Africa (De Abreu et al., 2013; De Kubber et al., 2011; Learmonth et al., 2015; Maree & Wright, 2010; Mosavel et al., 2009).

Within the South African context several factors should be considered when designing effective cervical cancer prevention and screening programmes. The demands of competing health needs, healthcare-infrastructure, and general socio-economic conditions should be taken into account (Denny, 2010). The HIV/AIDS epidemic in particular takes precedence in terms of the allocation of resources and places strain on healthcare-infrastructure (Tathiah et al., 2014), and as such must be considered in the development of cervical cancer screening practices. Optimal timing of implementing screening/prevention programmes is another important variable to consider.

2.2.1 Vaccination programme. The WHO recommends that vaccines protecting women against high risk HPV strains associated with cervical cancer be administered prior to sexual activity (Tathiah et al., 2014). Young women of school-going age (between 9 to 13 years) have thus become the target population of vaccination programmes. The implementation of HPV vaccination programmes involves the administration of dosages to each girl at specific intervals over a period of six months (Laubscher et al., 2015). This places importance on project co-ordination and vaccination monitoring to ensure that each child receives the correct dosage at the correct time. The first of such vaccinations programmes to be implemented in South Africa was known as the Vaccine and Cervical Cancer Screen (VACCS) project which was conducted in 2014 (Laubscher et al., 2015). This campaign targeted girls over 9 years of age (between grades 4 and 7) from schools in both the Western Cape and Gauteng. The chief logistical challenge in this project was obtaining informed

consent from both the parents and participants themselves. Adherence to the 6-month schedule also proved to be an obstacle (Laubscher et al., 2015).

Although data gathering regarding the efficacy of the HPV vaccination programme in South Africa is limited to my knowledge, research on the topic has been conducted in developed countries. Drolet et al., (2019) conducted a systematic review and meta-analysis of 65 articles pertaining to the effectiveness of HPV vaccination programmes in high income countries, and concluded that these programmes do in fact reduce infection rates of HPV strains significantly. By investigating the incidence of specific HPV strains five to eight years following vaccination, they found a marked reduction in the incidence of HPV strains 16 and 18 (83% in girls aged 13-19 and 66% in women aged 20-24 years) (Drolet et al., 2019). Such findings suggest that should South African implementation of vaccination programmes succeed in countering vaccine hesitation and improving participation in vaccination programmes, a marked decrease in the incidence of cervical cancer would be expected (Ngcobo, Burnett, Cooper, & Wiysonge, 2019).

The next line of defence in preventing the development of cervical cancer to it screen for abnormal cells in the cervix regularly; an indication of early stage development of cervical cancer.

2.2.2 Screening adherence. Screening adherence and the regular attendance of Pap smears is influenced by several factors in South Africa, which discourage the attendance of screening opportunities. Mosavel et al. (2009) specify that access to relevant medical facilities, the cost of regular Pap smears, fear of experiencing pain or discomfort during the procedure, a general distrust of the medical system and the time required to attend the clinic prevented women from attending regular screening opportunities. Maree and Wright's study echoed the finding related to the cost of Pap smears as they determined that approximately 45% of the women in their study were reluctant to spend money on their own health concerns

(2010). Uncertainty surrounding Pap smear practices and the long waiting periods for results have been found to compound the fear and apprehension experienced by women in anticipation of the procedure, and negatively influence screening attendance (Momberg, Botha, van der Merwe, & Moodley, 2017).

Momberg et al.'s study involved focus group discussions with 27 women from a colposcopy clinic in Cape Town, South Africa, and delved into those factors which motivated women to attend their initial Pap smears (2017). Findings indicated three dominant factors which encouraged women to pursue care: adverse physical symptoms such as abdominal pain, abnormal bleeding, painful urination, and vaginal discharge or itching; encouragement from influential individuals in their lives such as peers and heath care providers; and the perception that something was wrong with their womb. The last factor often arose from the belief that the womb needed to be cleansed in order to fall pregnant. Pap smears were considered as a diagnostic tool, rather than a preventative tool (Momberg et al., 2017), which indicated limited awareness pertaining to the primary preventative purpose of the procedure.

Resources dedicated to the prevention and improvement of screening adherence is vital in order to decrease the incidence of cervical cancer in South Africa, but part of research focus needs to be delegated to women who have been diagnosed with the disease and their experiences thereof. It is possible to reduce the burden of cervical cancer through education, promoting family involvement, and by using the media to promote knowledge and awareness about the disease (Leser & Francis, 2014). For this reason, there has been a surge in the number of campaigns seeking to raise awareness and understanding of cervical cancer and its symptoms (Maree & Wright, 2010).

2.3 Barriers to Cervical Cancer Care

A number of challenges have been encountered in South Africa with regards to services that promoting health and cervical cancer prevention efforts. Tathiah et al. (2014)

have suggested that the poor knowledge, attitudes and stigma associated with cervical cancer may be related to the limited accessibility to necessary resources such as trained healthcare providers, as well as constrained options with regards to treatment and palliative care for the disease. In addition, the legacy of Apartheid is evident in the discrepancy of attitudes and beliefs relating to cervical cancer between the various racial groups (Mosavel et al., 2009). Four themes arose when considering barriers to cervical cancer care, namely: the importance of knowledge, that women often encounter misinformation, the sources of information which women encounter, and fatalistic attitudes.

2.3.1 The importance of knowledge. A lack of knowledge pertaining to cervical cancer and the necessary preventative measures were found to be barriers to health-seeking behaviour among underprivileged urban women (De Abreu et al., 2013; Maree & Wright, 2010). This lack of knowledge contributes to what De Abreu et al. (2013) consider psychosocial barriers. One such barrier is the negative stigma associated with gynaecological cancers (De Abreu et al., 2013; Learmonth et al., 2015). Learmonth et al., (2015) included opposing cultural beliefs and language barriers. The relevance of stigma and culture will be discussed in more detail later in the review of literature.

A lack of knowledge regarding cancer has been indicated among samples of South African women. For example, Maree and Wright (2010) indicate that women reported low levels of knowledge about cancer in Tshwane, despite programmes directed at educating women about cervical cancer and available prevention efforts being easily accessible. Of the women in this study, 44.8% reported that they were unaware of what cervical cancer was, and a further 21.6% reported that they were unsure with regards to the facts of the disease, it's associated symptoms and the possible repercussions thereof (Maree & Wright, 2010). Another study conducted by Hogue and Hogue (2009) revealed similar findings with their sample of 389 university students. A lack of awareness regarding cervical cancer was

indicated as only 42.9% of their sample had heard of the disease. Furthermore, Maree et al. (2014) reported that limited understanding of the disease and the consequent treatment that women undergo was evident in their study. They insinuated that both insufficient knowledge and misinformation that was propagated from individuals within their communities may have attributed to this lack of understanding.

A lack of adequate knowledge is not exclusively attributed to the disadvantaged; well-educated women also present with poor knowledge and insight pertaining to the perceived personal risk of developing cervical cancer (Mosavel et al., 2009). It is imperative that accurate information about cervical cancer, and both the prevention and treatment thereof, be disseminated in an applicable manner (Pillay, 2002). The appropriate means of communicating and promoting knowledge needs to be suited to the setting and targeted population. Mosavel et al. (2009) reported that South African women often use nonmedical terms to construct the concept of cervical cancer and as such terms such as “cervix” would be foreign to them. In addition to the verbal conceptualisation of factors associated with cervical cancer, the quality of information being conveyed from various sources may also present a challenge.

2.3.2 Misinformation. Much information is propagated within social networks, and unfortunately much of what is communicated with regards to cervical cancer is inaccurate due to a shortage of knowledge (Maree et al., 2014). Surveys conducted with 1100 unscreened women in Zambia during a door-to-door community-based awareness initiative revealed that misconceptions and myths which are propagated about cervical cancer resulted in poor utilization of the screening opportunities which were available (Chirwa et al., 2011). Chirwa et al., (2011) provided several examples of the misconceptions associated with the cause of cervical cancer: that it is associated with bewitchment or a satanic curse, that it may

be caused by the use of oral contraceptives, and that it is a punishment associated with promiscuous behaviour or having an affair, to name but a few.

In terms of myths relating to the screening process for precancerous lesions, women reported feeling that their sexual activity and fertility would be compromised, that people would assume that they were HIV positive, and that the procedure would be invasive and painful (Chirwa et al., 2011). As a consequence of such myths and beliefs, treatment adherence may be negatively influenced (Learmonth et al., 2015). Mosavel, Simon, and Ahmed (2010) explain these consequences by describing how misinformation with regards to cancer solidifies negative perceptions and images of the disease thereby negatively influencing societal attitudes towards the disease. Poor community attitude towards cervical cancer reduces member receptiveness to cancer prevention strategies and may inhibit treatment adherence.

2.3.3 Sources of information. Women's cervical cancer screening practices and treatment adherence is heavily influenced by the attitudes and beliefs of other members within their communities (Maree & Wright, 2010; Mosavel et al., 2009). The manner in which women interpret and disseminate information regarding cervical cancer to those they encounter is influenced by the attitudes of other individuals that they are exposed to. How this information is shared within a community, as well as the source of this information, has an impact on the interpretation of this new information and the opinions that are formed in response to it (Leser & Francis, 2014). Subsequently, the perception that is created about cervical cancer influences how individuals with the disease are accepted and treated by others (Leser & Francis, 2014).

Reliable sources of information may lead to the development of accurate and healthy perceptions of cervical cancer. The 43% of the female university students in Hogue and Hogue's study, who were aware of cervical cancer, revealed that they obtained information

about the disease from community health workers, media sources, peers, parents, healthcare providers such as nurses, and other family members (2009). Community health workers proved to be most common source of information with approximately 22% of knowledgeable students reporting that they were the initial source of information, followed by healthcare providers (20%), the media (19%), and fellow students (16%). Parents identified as the initial source of information proved to be less prevalent with only 11% of women in the study reporting that they learnt about cervical cancer from a parent (Hogue & Hogue, 2009). The importance of healthcare provider relationships is evident as a source of information and will be discussed further in relation to their relevance as a component of a healthy support network for cervical cancer patients.

Despite the previous study indicating that a limited number of female students learned of cervical cancer from a parent, effective parent communication has been associated with a decrease in risky sexual behaviour and an increase in safe-sex practices (Leser & Francis, 2014). Parents and family members therefore have the potential to play a central role in the primary prevention of HPV and cervical cancer in daughters if information is conveyed early enough. Family members play an important role in the dissemination of information through communication, the health beliefs that they promote and the behaviour that they demonstrate (Mosavel et al., 2010). The information shared between mothers and daughters is of particular importance, regardless of in which direction the information is being propagated.

2.3.3.1 Mother-daughter communication. The mother- daughter or mother-child relationship presents an opportunity for propagating accurate information and insights regarding cervical cancer. Mosavel et al. (2010) conducted interviews with 157 mother-daughter pairs in Cape Town, South Africa in order to explore their cancer-related knowledge, and a strong concordance within the mother-daughter relationship emerged. Mothers and daughters share the associations they make with cancer and how they make

sense of the disease when queried about their fear responses to the concept of cancer. The study reported that 69% of mothers associated cancer with death and 43% with suffering and detrimental consequences, while 50% of daughters associated it with death and 42% with negative consequences (Mosavel et al., 2010). The tendency of mothers and daughters to share attitudes and beliefs indicates that the relationship is a potential asset for propagating information should one party be more aware of cervical cancer than the other.

An addition three studies have suggested that mother-child communication is essential in endorsing health related knowledge. Francis et al. (2011) led three focus groups in Johannesburg, South Africa involving 24 women between the ages of 18 and 24 exploring women's attitudes and beliefs pertaining to cervical cancer prevention, as well their response to communicating information surrounding sexuality within the mother-child dynamic. Findings indicated that the women communicated with their children regarding a broad range of sexual health issues, but were limited in their knowledge about HPV, the HPV vaccination and cervical cancer. The key finding from Leser and Francis's (2014) survey of 86 mothers in Johannesburg indicated that mothers demonstrated high self-efficacy with regards to their ability to communicate with their children about sexual health issues, but felt that they did not have enough information to convey, echoing the findings of Francis et al. (2011). It is imperative to equip mothers with adequate education and accurate information which they can disseminate to their children in order to raise awareness and insight into the disease and its prevention (Leser & Francis, 2014). Women demonstrate a desire to escape fear-generating messages and perceptions of cancer, but more information relating to the disease and lifestyle choices which promote a healthy lifestyle is necessary.

An alternative to the traditional mother-to-daughter communication trajectory exists; adolescent daughters have the potential to be a source of information for their mothers. Mosavel, Simon, and van Stade (2006) suggest that adolescents often display self-efficacy

and motivation to participate in health promotion opportunities, indicating that they could be an asset in disseminating gained information and knowledge. A reciprocal dynamic within the relationship between mothers and daughters was established in a survey conducted with 131 mothers and 145 adolescent daughters in Cape Town, South Africa (Mosavel et al., 2006). 93% of the mothers indicated that they were willing to listen to health-related advice from their daughters. The influence of adolescent daughters on mother's health-related knowledge and behaviour was explored, and it was determined that daughters play an active, influential role in supporting their mothers and promoting healthy behaviour. As such, the manner in which adolescents are viewed needs to be reformulated to allow for them to be considered sources of information about cervical cancer and potential agents of change within the family context in order to overcome barriers to health-seeking behaviour.

2.3.4 Fatalistic attitudes. Both a lack of information and incorrect information propagated by individuals who do not have accurate knowledge about cervical cancer contribute to fatalistic attitudes and beliefs about the disease. The belief that little to nothing can be done to prevent or cure a disease such as cervical cancer is associated with passiveness in seeking appropriate care (Mosavel et al., 2009). However, this survey of 228 women in Cape Town indicated that the majority of women still demonstrated health-seeking behaviour despite fatalistic attitudes. This implies an incongruence between beliefs and behaviour.

A lack of health education, fatalistic attitudes and the propagation of misinformation with regards to who is most likely to be affected by cervical cancer contributes to a reduction in perceived risk of the disease (Learmonth et al., 2015). Individuals therefore do not perceive the need for health-seeking behaviour to prevent the onset and progression of cervical cancer.

2.4 Health-seeking Behaviour

Gaining knowledge is associated with empowering individuals as they are better able to take control of their own health and well-being which promotes health-seeking behaviour. Maree and Wright (2010) describe health-seeking behaviour as those actions that individuals undertake in response to adverse symptoms to remedy perceived poor health. A study based in Mdantsane in the Eastern Cape found that women demonstrate both a general increase of awareness surrounding cervical cancer and greater desire to maintain health and well-being in response to a female cancer programme (De Kubber et al., 2011). According to this cross-sectional study, 66% of the 532 female participants who were exposed to an awareness campaign where information about cervical cancer was conveyed to them via nurses and word of mouth acknowledged an increased awareness of the disease. This translated to increased screening adherence at primary health clinics.

The association between increased awareness of cervical cancer due to increased exposure to information and improved screening attendance was confirmed in the study by De Abreu et al. (2013). Research conducted among disadvantaged women situated in informal settlements around Cape Town indicated that access to information about screening procedures, a desire for symptom relief and taking responsibility for one's own health status acted as facilitators for women to attend the described screening practices. An important factor in seeking medical attention is the individual's perception of the worthiness of their care (Maree & Wright, 2010). Cultural beliefs influence such perceptions, especially in relation to the traditional gender roles that are held by women in South Africa. Fatalistic attitudes in response to a diagnosis as well as the idea that a lack of symptoms equate to health hinder health-seeking behaviour.

2.5 The Role of Culture

Attitudes and beliefs surrounding cancer are partly shaped by culture (Learmonth et al, 2015; Maree & Wright, 2010). Cultural beliefs and the resultant social attitude towards cancer can have a significant effect on the manner in which an individual perceives themselves, the disease itself as well as their future (Noor-Mahomed, Schlebusch, & Bosch, 2003). Cultural factors influence the perception of gynaecological cancers as cultural beliefs shape the manner in which women perceive and react to a cervical cancer diagnosis; it affects decision-making in terms of health-seeking behaviour in both spiritual and social contexts, and when approaching health-care practitioners (Maree et al., 2014). Women's attitudes towards the disease are therefore shaped by their cultural beliefs and attitudes, which may influence their perception of their treatment experience. These beliefs also contribute to several barriers to seeking appropriate medical care as they may encourage misconceptions about cervical cancer (Mosavel et al., 2009).

Maree and Wright (2010) assert that there is a discrepancy between Western and African cultures with regards to how women approach health-seeking behaviour. Self-reliance and the achievement of personal goals forms a major facet in Western cultures, whereas African cultures emphasise interconnectedness between individuals and interrelatedness to others and ancestry. The opinions of others are therefore of great importance in African contexts, and the emotional burden of isolation and rejection due to noncompliance with cultural norms must be considered when interpreting behaviour (Maree et al., 2014). Sociocultural beliefs underpin stigmatic ideas and mistrust for conventional/Western medical systems (Learmonth et al., 2015), and influence who women will approach when seeking care.

2.5.1 Religious and spiritual beliefs. Religious or spiritual beliefs may influence how individuals make sense of both the symptoms of a disease and its causes. Jansen van

Rensburg, Maree, and Casteleijn (2017) explored the quality of life of cancer patients and confirmed that spiritual factors played an influential role during their experience. Spirituality was reported to have the potential to give patients hope and peace during their experience, and ultimately contributed to improved quality of life.

Women may perceive a spiritual element in relation to their disease which motivates them to primarily consult traditional healers with the goal of alleviating symptoms (Maree et al., 2014). Cervical cancer is frequently contextualised within sociocultural beliefs as the explanations provided echo the individual's personal beliefs (Learmonth et al., 2015). Women from rural areas in particular consult with traditional healers with regards to sexual, reproductive and genito-urinary health issues (Pillay, 2002). Such women are inclined to seek conventional treatment once traditional options have failed, which indicates the need for a collaboration between traditional and conventional medicine. Dutta, Haderxhanaj, Agley, Jayawardene, & Meyerson (2018) propose that the correlation between screening practices and religious beliefs is an extension of traditional gender constructs. If culture and religion influence the perception of screening as being incompatible with their beliefs, screening adherence may be negatively influenced.

2.5.2 Gender roles. Religious and cultural beliefs may influence social and community attitudes towards women who have been diagnosed with cervical cancer and other gynaecological cancers (Maree & Wright, 2010). The gender bias associated with gynaecological conditions is also shaped by cultural beliefs. A culture of masculinity in the South African context promotes the disregard of gender rights and enforces defined gender roles (Maree & Wright, 2010). South African women (black women in particular), commonly inhabit a subordinate, submissive position both within the family unit and within society according to Learmonth et al. (2015). The extensive impact of negative masculine views regarding gynaecological cancers, and the aligned stigma resulting from the perceived

link between such conditions and sexually transmitted disease and promiscuity, is apparent. Women conveyed a fear of abandonment by their partners or husbands due to their diagnosis, and the potential removal of emotional and financial support which could result (Learmonth et al., 2015). Screening adherence is therefore negatively influenced as women are apprehensive of the possible implications of a cervical cancer diagnosis.

Women who are subjected to such rigid subordinate gender roles may experience control from an abusive partner; limiting their access to instrumental forms of support such as financial provision when seeking medical care for cervical cancer. Dutta et al. (2018) conducted an analysis of secondary data related to questions about cervical cancer screening and intimate partner violence in Kenya. Questions were posed to 3222 women during the Kenyan Demographic and Health Survey. Their study revealed that those women who experienced IPV were less likely to attend screening opportunities as there was a risk of further exposure to abuse from their partners (Dutta et al., 2018). Not only was the negative stigma surrounding the disease itself indicated as a contributing factor to such behaviour, but also that there was a negative stigma surrounding the screening practice itself. Certain women who attended screening opportunities such as Pap smears were considered by their husbands to be admitting to adulterous behaviour.

2.6 Stigma

Mosavel et al. (2010) indicated that both community and cultural factors influences how individuals interpret illness. Such factors act as a source for negative perceptions and stigma associated with a disease like cervical cancer. Within the South African context, cervical cancer carries a negative association with promiscuity, fatalistic attitudes from both the individual and those surrounding them, and the belief that the disease is caused by a curse or being ill-fated (Chirwa et al., 2011). The stigma surrounding this form of gynaecological cancer is the driving force behind these negative beliefs, and may lead individuals within the

community to be discouraging to women with cervical cancer. A lack of knowledge and insight with regards to the prognosis of disease such as cervical cancer among community members contributes to a negative outlook for the future, which could be conveyed to patients (Maree et al., 2014).

An example of detrimental stigmatic ideas is those which create an association between HIV/AIDS and cervical cancer. According to Momberg et al. (2017), a negative association between clinic attendance and the assumption about being HIV-positive was evident. Focus group discussions in their study revealed that women were fearful of others assuming that they were HIV-positive when they were seen attending cervical cancer clinics. Apart from considering the perceptions of others within their communities, these women also indicated that they were fearful of being tested for HIV and of receiving a positive diagnosis at the clinic. This is an example of how both communities and individuals are susceptible to stigmatic ideas based on lacking or false information, which ultimately hinders health-seeking behaviour.

Stigma plays an influential role in potentially diminishing social support for women with cervical cancer. Maree et al. (2014) suggested that limited support due to stigmatising conceptions has been associated with patients reporting feelings of isolation, and have contributed to reported suicidal thoughts and realisations. A study conducted by Sabulei and Maree (2019) echoed these ideas. Structured interviews were conducted with 153 women in order to describe their quality of life during or following treatment for cervical cancer. Role, physical, cognitive, emotional and social functioning were specifically measured, and they found that social functioning was the most suppressed amongst their sample of participants (Sabulei & Maree, 2019). Sabulei and Maree (2019) concluded that the adverse cervical cancer symptoms that women experienced in association with being stigmatised against contributed to social isolation and the resultant suppression which further impacted quality of

life. In order to counteract the stigma and misconceptions surrounding cervical cancer it is important to facilitate the dissemination of accurate information at a community level (Momberg et al., 2017), both through interactions with health-care providers and within social networks.

2.7 Social Support

Regardless of the severity of the symptoms associated with a disease, social support in the form of a supportive social network is beneficial to the individual. Taylor (2015) defines social support as that information which one receives (or perceives) from others to indicate that they are cared-for and loved, and that they are a valued constituent of a network involving reciprocal communication and obligations. For the purpose of this discussion it is important to distinguish between perceived social support and the provision of actual recieved support before commencing with the functional categories of social support. Gülaçtı (2010) describes how perceived social support relates more to how a person subjectively interprets the quality of the support they receive; their impression thereof. On the other hand, received support relates more to the objective functional categorization of social support.

2.7.1 Functional categories of social support. The names given to the functional categories of social support vary across the reviewed studies but are mostly derived from the work of Cohen and Wills (1985). For the purpose of this thesis the designations emotional, informational and instrumental support, as well as social companionship, will be employed.

Emotional support refers to information provided by other individuals that communicates acceptance, nurturance and reassurance; it indicates to the person that they are valued and cared for (Cohen & Wills, 1985; Taylor, 2015). This form of support enables the individual to face stressful events with confidence in knowing the worth of the position they hold within their social network. Informational support is the advice conveyed which promotes an understanding of adverse events and how to cope with them (Cohen & Wills,

1985). Sources of particular importance with relation to reliable informational support are individuals who have been exposed to the same or similar stressful event (Taylor, 2015). Healthcare-providers have the potential to provide informational support with regards to illnesses such as cervical cancer. Instrumental support entails the provision of tangible material resources, financial support and necessary services with the purpose of alleviating a degree of responsibility from the individual (Cohen & Wills, 1985; Taylor, 2015). A consequence of such support is that it creates time for the individual to perform other tasks. The final form of support identified by Cohen and Wills (1985) is social companionship which creates a sense of affiliation and belonging and may distract the individual from their stressors.

Each form of social support presents varying buffering benefits according to Carpenter, Fowler, Maxwell, and Andersen (2010), who explored the role of material aids and companionship in buffering against traumatic stress which may arise from the persistent symptoms associated with gynaecological cancers. Companionship and having someone to confide in acted as a greater buffer against the negative psychological consequences of the disease than material aids in times of stress (Carpenter et al., 2010). This is congruent with the findings of Kebele and Kebele (2017), who indicated that having a supportive friend or companion enabled women with cervical cancer to better cope with their disease. Interestingly, it was noted that the source of companionship played an important role. Friend support rather than family support was found to be more beneficial in terms of companionship. Carpenter et al. (2010) postulate that this may be due to family members experiencing adverse psychological effects in response to their loved one's negative experiences.

2.7.2 Possible sources of social support. Social support networks typically include partners, family members/relatives, friends, and those individuals that one comes into contact

with through social and community interactions (Taylor, 2015). Interactions with healthcare-providers is also of importance and forms a vital part of a support network when encountering health issues.

2.7.2.1 Interactions with healthcare providers. Interactions between healthcare-providers and patients hold a significant position (Maree et al., 2014). Women interact with several healthcare practitioners from the time that they approach a clinic for a physical examination or Pap smear, through the progression from a diagnosis until treatment, and beyond for scheduled check-ups. The manner in which the patient perceives these interactions and the information they receive influences their attitude towards the prognosis of cervical cancer. Patient experiences of the services provided and the identity of the practitioner in terms of age, gender and their spoken language influences their perception of the interaction (Learmonth et al., 2015). Negative interactions with healthcare services foster negative patient attitudes and experiences, as well as misconceptions about the disease and treatment (Maree et al., 2014).

As previously indicated, healthcare providers are an important source of information for cervical cancer patients, and it is the responsibility of healthcare providers to communicate information to their patients. Momberg et al. (2017) established that women in their Cape Town study felt that they either did not receive adequate information from primary healthcare providers with regards to their condition and the treatment that they were scheduled to undergo, or did not adequately understand that which was being communicated to them. A negative perception of the interaction resulted, which influenced women's perception of the relationship between themselves and their healthcare providers as a source of support during their journey following a positive diagnosis with cervical cancer.

In order to foster positive experiences with healthcare services focus needs to shift to a context broader than just the Pap smear attendance associated with screening practices

which typically receives attention. Mosavel et al. (2009) suggested that resources need to be delegated to the procedures that follow the actual Pap smear; the steps in processing Pap smears and returning results timeously, in developing efficient follow up and referral systems, in creating centres specifically for lesions detected early, and for putting systems in place for those individuals with advanced disease (Mosavel et al., 2009). Efficiency in these areas will improve interactions between patients and healthcare providers and has the potential to foster trust in the healthcare system ultimately improving both diagnostic and treatment experiences.

2.7.2.2 Life-partner support. Maree, Mosalo and Wright (2013) explored the role of life-partner support during cervical cancer treatment and the manner in which the state of the relationship influences a women's attitude towards treatment and experience thereof. The perceived support varied among participants and it was suggested that factors such as the concealment of a cervical cancer diagnosis and the symptoms thereof, altered sexual relations, and insufficient partner understanding of the disease affected the degree and quality of support that women perceived (Maree et al., 2013). Interactions between women and their partners during cervical cancer treatment have previously been explored: studies have focused on the negative influence of the disease on partner interactions (De Groot et al., 2005), and more specifically on sexual functioning of women both during and following treatment (Cull et al., 1993; Maree et al., 2013; Ntinga & Maree, 2015).

Research indicates that both men and women experience disruptions in their relationships when a woman undergoes treatment for cervical cancer. De Groot et al. (2005) conducted a survey with couples where the women were survivors of cervical cancer (having completed treatment within two years of the survey). The study explored both partners' perceptions of the psychosocial impact of the disease itself and its treatment. As expected,

disruptions to intimacy were reported, but negative influences on instrumental life domains were also indicated which further disrupted relations and subsequent well-being.

2.7.3 Possible effects of social support. Adequate social support is associated with positive outcome in both psychological and physical health. The role that social support plays in mediating the effect of stress on well-being has been explored extensively. Taylor (2015) indicated that social support has the potential to moderate the effects of stress, dulling the effects thereof when it exceeds normal levels (buffering hypothesis), such as is evident during the experience of treatment for life-threatening disease. Research suggests that social support benefits the individual in three distinct ways (Agudile, 2018): it provides direct assistance as the individuals needs for reassurance, intimacy and social belonging are met, it promotes the utilization of both community and individual coping resources which buffers against the negative influence of stressors, and promotes health-related behaviour due to exposure to supportive social networks.

Carpenter et al. (2010) report that social support may be an intervening variable in decreasing the distress associated with survivorship trajectory of cancer; they questioned whether social support in fact acts as a buffer during periods of distress. A lesser degree of social support is associated with poorer quality of life, yet greater social support is associated with improved psychological outcomes. With regards to long-term outcomes of gynaecological cancers, the distress is associated with persistent symptoms, sexual morbidity, and the covariance of both psychological and physical outcomes (Carpenter et al., 2010). Their study indicated that better social support (both structural and functional in form) along with fewer physical symptoms were associated with a less traumatic experience of physical symptoms and fewer depressive symptoms. Effective social support influenced how women perceived and interpreted their traumatic experiences, allowing for better integration of these events associated with their disease and improved psychological outcomes (Carpenter et al.,

2010). Adverse treatment effects combined with the stigma, discouragement, and subsequent lack of perceived support within the social setting contribute isolation and suicidal thoughts (Maree et al., 2014; Noor-Mahomed et al., 2003).

2.8 Subjective Well-being During and After Treatment

The physical symptoms associated with gynaecological cancers and their treatments have been demonstrated to be a source of profound psychological distress (Maree et al., 2014; Carpenter et al., 2010). Persistent physical symptoms combined with an inadequate support network contribute to increased distress associated with the disease and therefore influence well-being. Maree et al. (2014) indicated that the way in which women describe treatment for cervical cancer can be shaped either positively or negatively; positively in that they may consider it to be a means by which symptoms such as pain and bleeding is alleviated, or negatively in that treatment itself contributes to pain, fatigue and presents logistical challenges with regards to activities of daily life. This perception in turn influences their subjective well-being. Unfortunately, many women considered cervical cancer to be associated with suffering which ultimately underwrote fatalistic and suicidal ideas (Maree et al., 2014; Noor-Mahomed et al., 2003).

De Groot et al. (2005) suggested that the psychosocial factors associated with cervical cancer outlast the physical, thereby influencing well-being after the cessation of treatment. Concerns with regards to the fear of recurrence of the cancer, changes to one's self-concept (such as decreased self-confidence), relation concerns, diminished work proficiency as well as persistent stigma contributed to both short- and long-term concerns (De Groot et al., 2005). Psychosexual concerns as a result of both physical and psychological treatment effects are also of major concern (Carter, Stabile, Gunn, & Sonoda., 2013).

Collectively, the above studies forming part of the review of literature indicate that various factors influence health-seeking behaviour, subjective well-being and the experience

of disease. Psychosocial factors such as negative stigma, opposing cultural beliefs, inadequate/false knowledge and a lack of perceived social support contribute to poor receptiveness to screening opportunities, a lack of health-seeking behaviour and a negative experience of treatment. In contrast to these negative influencers; effective diagnostic and treatment procedures, a positive relationship with healthcare providers which promotes trust, gained knowledge, a supportive social network (especially from a partner), and the perceived worthiness of care act as protective factors which promote the well-being of the individual. The interplay of these factors in determining the psychosocial experiences of women who have undergone treatment for cervical cancer, along with their physical and emotional experiences, can be conceptualised using the illness intrusiveness theoretical framework.

2.9 The Illness Intrusiveness Theoretical Framework

Research has revealed several factors which influence a women's well-being both during and after cervical cancer treatment. The illness intrusiveness theoretical framework (Devins et al., 2001; Devins, Bezjak, Mah, Loblaw, & Gotowiec, 2006; Devins, 2010; Mah, Bezjak, Loblaw, Gotowiec, & Devins, 2011) proposes a model which describes the influence of psychosocial factors and transformations associated with chronic diseases, such as cancer.

2.9.1 Model of illness intrusiveness. This model describes the manner in which chronic or life-threatening diseases affect subjective well-being via the influence of several moderating and intervening variables (Devins et al., 2006). According to Devins et al. (2001), illness intrusiveness signifies the influence of illness-related factors on patients' well-being and quality of life when they experience chronic illness by disrupting their lifestyle, interests and participation in normal daily activities.

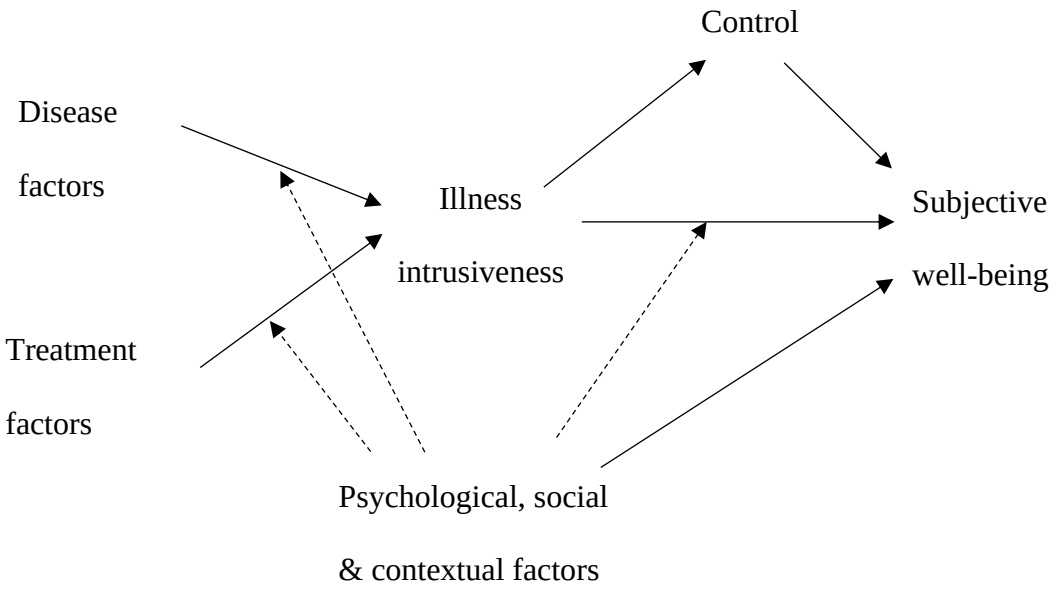

Figure 1. The illness intrusiveness theoretical framework. The effect of both disease and treatment factors indirectly influence subjective well-being via the intervening variable, illness intrusiveness, which exerts a direct effect on well-being and an indirect effect of perceived personal control. Moderating effects as a result of the psychological, social and contextual factors are indicated but dashed arrows (Devins, 2010, pp. 529).

The main hypothesis of the theory postulates that both disease (such as fatigue or pain) and treatment factors (such as persistent side effects and inability to work) indirectly influence subjective well-being and the concurrent development of emotional distress via their effect on an intervening variable known as illness intrusiveness (Devins et al., 2001; Devins et al., 2006; Mah et al., 2011). Three main life domains comprise illness intrusiveness: (a) relationships and personal development (such as community involvement, social interactions personal and religious expression); (b) intimacy (such as partner relations and sexual functioning); and (c) instrumental domains (such as work life, health status, and economic circumstances) (Devins et al., 2006; Mah et al., 2011). Although illness intrusiveness is the intervening variable in this relationship; psychological, social and

contextual factors play an important role as moderating variables (Devins et al., 2006; Mah et al., 2011). The discussed variables and how they relate are depicted in Figure 1.

This model is useful in conceptualising the burden of a disease and the psychosocial implications experienced by the patient (Devins et al., 2001). It acknowledges that various factors influence the patient throughout the duration of treatment, as well as after its completion, and that the ensuing limitations may be moderated by both psychosocial and contextual factors (e.g., socioeconomic status and age) (Devins et al., 2006). Psychosocial factors are differentiated according to whether they have an impact on the experience of a disease, or whether they occur as a result of factors associated with the disease itself (Devins et al., 2006), Ultimately, these factors then moderate the possible effect of illness on subjective well-being.

The illness intrusiveness model has previously been applied to investigate lifestyle disturbances caused by numerous cancers including breast and prostate cancer. Mah et al. (2011) confirmed that maintaining involvement in activities which are of significance to individuals (such as intimate relationships with partners and child care) was challenging. Disruptions in such areas of daily life had a negative influence on subjective well-being and caused substantial emotional distress (Mah et al., 2011).

In application to cervical cancer and its intrusiveness in relation to subjective well-being, lingering physical effects such as interrupted daily activities in terms of childcare, disruptions to intimate relationships and work disturbances are anticipated. Disease factors such as pain, bleeding, fatigue and undesirable discharge are distinct from treatment factors such as tissue damage, pain, fatigue, and nausea (to name but a few), yet certain features such as depression, anxiety and stigma may arise as a consequence of either factor (Devins, 2010). Also, worth noting in relation to cervical cancer is that the quality of social support features heavily within the domains of illness intrusiveness described above. The illness intrusiveness

theoretical framework provides a contextual lens through which the impact of a disease such as cervical cancer on subjective well-being may be understood.

2.9.2 Limitations of the framework. In a study conducted with the purpose of exploring the moderating effect of contextual factors on illness intrusiveness in six common cancers, certain limitations were identified (Devins et al., 2006). Devins et al. (2006) explain that an overarching limitation within the framework is that the direct causal effect of moderating variables cannot be assumed; the manner in which they exert influence is a process yet to be determined. The ability to draw causal inferences is therefore hindered, and further rigorous research is necessary to corroborate initial findings with regards to the framework. Although this is an important limitation to consider, it is not particularly pertinent to this study which is explorative in nature rather than explanatory.

In summary, the illness intrusiveness theoretical framework provides an explanation of how adverse symptoms associated with a disease, treatment experience and the interaction of psychosocial factors interact to have a resultant influence on well-being. This framework guided me to better understand how a disease such as cervical cancer may affect a woman during her diagnosis, treatment and recovery. It allowed me to conceptualise what was gleaned through the review of relevant literature (such as that relating to the influence of social support, fatalistic cognitions, and the experience of stigma) in terms of where these factors may be situated within the model. As such, the illness intrusiveness theoretical framework was suitable for exploring the psychosocial experiences of women throughout the trajectory of cervical cancer and its treatment.

2.10 Conclusion

As previously established, the majority of research in South Africa has focused on prevention and screening adherence. It is imperative that the incidence of new diagnoses be reduced, but focus should also be extended to the experience of cervical cancer and its

treatment due to the prevalence and burden of this disease in South Africa. De Groot et al. (2005) suggests that the psychosocial symptoms of cervical cancer in particular may outlast the purely physical symptoms leading one to question what the overall impact of such a disease on an individual's life may be. Both long- and short-term concerns are indicated; a fear of recurrence of the disease once treatment ceases, changes to the patient's self-concept related to feelings of confidence and attractiveness, relational concerns in terms of partner attitudes, and a diminished ability to perform instrumental tasks (De Groot et al., 2005).

Studies which addressed women's experiences of cervical cancer and the diagnosis thereof mostly focussed on specific topics such as partner support and relations during treatment (Maree et al., 2013), and not on the holistic experience of the disease and those psychosocial factors which have an impact on their subjective well-being in the South African context. Also, much of that which has been researched in terms of psychosocial experiences utilised quantitative methodologies, indicating a dearth in the of literature pertaining to women's unique descriptions and perceptions of their experiences of cervical cancer. By immersing myself in the personal accounts of women's experiences of cervical cancer and its treatment in conjunction with the understanding gleaned from the illness intrusiveness theoretical framework I was able to better consider the psychosocial experience of these women as well as the resultant effects on subjective well-being.

Chapter 3
Research Methodology

3.1 Introduction

In this chapter, I describe the methodology which informed the current research. I describe the environment from which participants were recruited, the criteria which needed to be considered for participants to form part of my study, the data collection method as well as my analytical framework. I also reflect on my experience of conducting this research and discuss ethical considerations.

3.2 Design

This was an exploratory study which employed qualitative methods in the form of semi-structured interviews to research the psychosocial impact of cervical cancer on the lives of women who had undergone curative treatment for the disease in South Africa. Exploratory research seeks to address new areas of research; phenomena that have not yet been studied (Bless et al., 2013). The objective of such research is to better understand a phenomenon through an adaptable approach instead of offering a solution to an existing problem. Exploratory objectives align with those of qualitative methods which serve to describe, explore and explain certain phenomena (Suter, 2012), in order to derive meaning and understanding surrounding the topic of concern. The use of qualitative methods such as in-depth semi-structured interviews allowed for unlimited responses from the study participants about their subjective experiences of cervical cancer, thereby creating rich linguistic data that could be analysed using thematic analysis to establish recurring themes. Limited qualitative research regarding women's experiences of cervical cancer has been conducted, specifically within the Western Cape, which contributes to the appropriateness of this approach.

3.3 Recruitment of Participants

I recruited participants using purposive sampling methods from the Radiation Oncology Department at Tygerberg Hospital, in South Africa. The unit receives patient

referrals from a multitude of clinics and hospitals in the surrounding areas ensuring a multi-ethnic and culturally diverse sample of participants. Over a period of 15 months, 15 participants were interviewed.

In order for women to be eligible for the study they had to be between the ages of 18 and 50 years old and have undergone curative treatment for invasive cervical cancer, which resolved no more than 18 months prior to interviewing them. Women over 50 years of age were excluded from this study as they may demonstrate different experiences than their younger counterparts in relation to their cervical cancer treatment. Women in their 60's and 70's may encounter different psychosocial challenges to women in their 30's and 40's, such as those related to fertility or childrearing.

The interviews were conducted in either English or Afrikaans, which limited the study to women who speak and understand either of these languages. I personally conducted the interviews and no translators were consulted, which limited the study to the languages in which I am fluent while excluding other languages such as isiXhosa. Participants provided written consent prior to data gathering in order to be included in the study, and gave permission for the interviews to be recorded.

Participants were recruited with the guidance of doctors, nurses and administrators working in the unit. The staff were aware of what the study entailed and could identify patients who met the inclusion criteria. Participants were either recruited from the follow-up clinic or the clinic which tends to women undergoing treatment.

Upon arriving at the clinic, Prof Simonds and I reviewed the list of patients expected to arrive for consultations on the day, as not all patients were suitable for my study. Prof Simonds checked the age of each woman, the type of cancer that they had been treated for and the duration since they completed treatment to confirm that the patients met the inclusion criteria. With this information I compiled a list of potential participants. Prof Simonds

indicated when a specific patient was receiving palliative care or that they were experiencing a recurrence of disease factors. I adjusted the list accordingly to exclude these patients. No information pertaining to other patients was disclosed.

As women were waiting in line for their appointments, I would call them individually by name to join me in a private consultation room. I then provided patients with a flyer describing my study (please refer to Appendix A), its objectives and reasons why they were asked to participate. We discussed the principles of confidentiality and consent; I stressed to them that participation in the study was completely voluntary and that there would be no negative consequences for them should they choose not participate or to leave the study at any time. A time, date and suitable venue were organised at the participant's convenience to meet for the interview. Patients could then re-join the line without concern of losing their place in the queue to see the doctor. The number of potential participants varied from one or two to five in each clinic, but often times there would be no appropriate patients. Meeting times were confirmed telephonically during the week before the interview.

3.4 Data Collection Procedure

My co-supervisor, Prof Hannah Simonds from the Radiation Oncology Department made a consultation room available for me to interview participants, which allowed for a private and undisturbed environment. I arranged to meet at the patient's home if it proved to be inconvenient for them to return to the clinic. Of the 15 interviews, 11 were conducted at participants homes upon their request. The interviews lasted between 20 and 70 minutes. At the onset of each meeting I reiterated to the participants that their identity and anything that they chose to reveal during the interview would remain confidential and that their identities would at no point be disclosed, and that they were free to terminate the interview at any point without negative consequences. I obtained written consent from each participant before initiating the interview. Thereafter I gathered demographic details about the participant

relating to age, stage of cancer at diagnosis, race, education, employment status and living environment. The forms used to obtain informed consent (please refer to Appendix B) as well as demographic details (please refer to Appendix C) are attached as appendices.

I conducted the semi-structured interviews with the assistance of an interview schedule (please refer to Appendix D) which directed the conversation. I formulated these questions under the guidance of my supervisor (Dr Roomaney) with the research question and aims of the study in mind. Over and above these considerations, the illness intrusiveness theoretical framework informed my interview schedule development. Using the framework as a reference, I developed questions to explore women's experiences of the diagnosis process as well as disease and treatment symptomology (aligning with the disease and treatment factors of the model). Questions were designed to explore women's thoughts and feelings during the trajectory of their disease, how they perceived their interactions with family and community members, and healthcare providers as well as the stigmatic ideas they may have encountered or projected themselves (encompassing some of the psychosocial factors in the model). Exploring participants perceptions of social support and their knowledge relating to the disease was also informed by understanding the dynamics illness intrusiveness. By considering these factors I was better able to develop the interview schedule. The goal was to prompt participants to explore their own thoughts and feelings regarding their experiences so that I could better understand the influence of cervical cancer on women's well-being.

The interview was recorded using a digital voice recorder. Those participants who travelled to the clinic for interviews were given a R100 contribution towards transportation to and from the interview, and a R50 Shoprite voucher was given to each participant as a token of appreciation for their willingness to participate in the study. After the interview concluded I reflected on the meeting and recorded any notes or impressions made during the interview. The interview recording was transferred to a private and secure laptop as soon as possible.

I transcribed the English interviews myself and outsourced the transcribing of Afrikaans interviews to a reputable research assistant, who signed a confidentiality agreement. I checked all transcriptions for accuracy. No translations were necessary as the interviews were analysed in their original languages to ensure authenticity.

3.5 Data Analysis

Participants provided in-depth accounts of their personal experiences of being both diagnosed and treated for cervical cancer. I analysed the transcribed interviews using the steps of thematic analysis as described by Braun and Clarke (2006), in order to extract meaning from the rich data. Firstly, I immersed myself in the data by familiarising myself with the content of the interviews by listening to the individual interviews again while reviewing its transcription for accuracy. I noted any themes that arose and thoughts linked to the notes I took down during the interview. Once this step was completed, I uploaded the transcription document to the ATLAS.ti programme to organise the data. The data was then analysed to identify recurring themes within the data from all the interviews. This process occurred over several steps.

Codes were generated to highlight interesting information across the entire data sets (Braun & Clarke, 2006). I noted any concepts that arose from my review of literature and theoretical framework (such as types of support) which could possibly be used as codes throughout the documents. I then analysed the transcriptions line by line, generating codes that described the specific excerpts. At times, more than one code was applicable to specific extracts, or extracts would extend to include more information linking to a specific code. This was due to multiple themes being present in a single excerpt, or overlapping ideas over several lines. Once I had coded all 15 transcriptions, I reviewed the code book checking for repetitions and refined their names.

The codes were then grouped into potential themes and subthemes as advised by Braun and Clarke (2006). I categorised the codes into groups linked to broader themes, quickly detecting that several major themes were emerging. I then refined the broader themes into more specific interrelated subthemes to which I could assign the codes. These themes represented my potential themes which could be reviewed for relevance and strength within the data set. Following this step, the themes were reviewed to make certain that they were relevant to each data set and coded phrase or extract from the transcribed data (Braun & Clarke, 2006). I established which codes and related themes were emerging most frequently in the data sets, and how closely related these themes were. This process allowed me to eliminate those themes which were not as prevalent or which were outliers in terms of relevance. I then named and clearly defined those themes before compiling them into a report.

Transcription and data analysis were conducted concurrently with the interviews in order to establish the point when data saturation was reached. According to Singh (2007), data saturation occurs when no new themes are being identified; the information that is being obtained from participants becomes redundant. This indicated that no new data was required for thematic analysis as no new information was likely to be obtained, and data collection could be halted.

3.6 Trustworthiness of the Study

In order to ensure the trustworthiness of the study it was important that I was adequately trained and guided in both conducting interviews and analysing the emerging data, and that my supervisor (Dr Roomaney) was included in the study at every step. Teachings at Stellenbosch University were also provided with regards to ethical conduct, conducting interviews, as well as transcribing and analysing data using thematic analysis as part of the Master's programme. Dr Roomaney and I conducted a mock interview where I

conducted an interview with her using the same interview schedule that I used to interview the participants of the study. This process allowed Dr Roomaney to observe my interview skills and provide constructive feedback which influenced my behaviour in future interviews. The role of the supervisor is vitally important in ensuring trustworthiness, and as such she was included in the planning, transcribing and thematic analysis phases of the study. Dr Roomaney had access to all interviews to be able to monitor the data, a fact that was communicated to participants when obtaining their written consent.

Lincoln and Guba (1986) proposed four criteria, which I applied, in order to improve the trustworthiness of this study. I made sure that the study was credible by engaging with both the participants and the context of the study in terms of the environment and disease, by seeking respondent reactions to my interpretations of their interview responses in the form of member checks, and by engaging in peer debriefings to achieve emotional catharsis during my engagement with the study environment. I ensured that the findings of my study are transferable to research or areas of interest in a similar context. Lastly, I sought the assistance of my supervisor in checking the dependability of the methodological processes that I utilised, and the confirmability of the data outcomes and interpretations that I made following data analysis (Lincoln & Guba, 1986).

3.7 Reflexivity

Women's health and taking responsibility for one's own health-seeking behaviour and self-care has always been important to me. This spurred on my interest in the field of health psychology, especially relating to women and the interplay between physical and emotional well-being. In my home, conversations relating to health matters were common; curiosity and transparency were encouraged in a safe, non-judgemental environment. Perhaps due to this, learning about the stigma that women are exposed to relating to gynaecological cancers was so surprising.

Upon meeting with Prof Simonds and Dr Roomaney it became clear that women's experiences once they were diagnosed with a disease such as cervical cancer may be different to what I expected. Prof Simonds conveyed information about the interactions that she had had with patients; about the trials they faced in terms of partner support and judgment from within their communities, as well as instrumental restrictions relating to financial strain. I realised that I had been viewing gynaecological cancers from a point of privilege. The women that I have known to have such conditions did not face judgement or rejection from those surrounding them, but rather support and empathy. Financial constraints were also not a consideration for these individuals; at least not in the way that it was for the women in this study. This conversation allowed me to check my preconceived ideas relating to cervical cancer and the women who undergo treatment for it, directing me to explore their unique experiences through open and empathetic conversations.

Reflexivity requires that a researcher take responsibility for the position they hold within the research, and be aware of any power dynamic and the effects thereof that may arise within the research setting (Berger, 2015). It was important to me that I was not an imposition within the clinical setting; to not disrupt the flow of the clinic or detract from the work that nurses or doctors needed to do. In terms of interacting with patients, I was keenly aware of the power dynamic which would develop if left to. Even during recruitment, possible participants would often call me 'Doctor' or Ma'am when I asked them to join me in an office to discuss the study objectives. At the time, I was concerned that women would feel coerced to take part in the study, so took time to dispel these notions by reminding them that I was a student and wanted to have a conversation with them regarding their experiences. I wanted these women to know that their contributions were valuable and meaningful, and served a greater purpose than just my curiosity.

It was incredibly rewarding to witness the strength and resilience of these women, and I feel fortunate to have often times been the only person that they could have open and honest conversations with regarding their experiences. The accounts of their experiences were moving, and their openness and transparency required that I check the emotions that I felt in response to what they were revealing to me. The positivity that many of them emanated was contagious, and I often left the interviews feeling invested in these women's well-being. These women had faced such adversity yet were encouraging to both myself and others who were undergoing treatment. I have gained an abundance of respect for the women in this study and the healthcare providers who care for them, and am more motivated than ever to expose the trials that they faced in order to raise awareness and empathy for such experiences.

3.8 Ethical Considerations

This study was approved by the Health Research Ethics Committee of Stellenbosch University (S17/10/202) (please refer to Appendix E) and permission was granted by the appropriate authority (Western Cape Department of Health) (refer to Appendix F) before participants were approached and data was gathered. At no point were the participants' well-being, either physical or psychological, at risk. Participants were free to leave the study at any point without negative consequences, yet no participants felt the need to do so. Should I have deemed that a participant required counselling, or if they requested counselling services themselves, I would have referred them to either Welgevallen Community Psychology Clinic in Stellenbosch or to Hope House Counselling Centre, depending on which was convenient for them to access. Hope House has three locations (in Bergvliet, Kuilsriver and Tableview), which provides options which may be closer to participants place of residence. No participant demonstrated distress, but I did refer two participants to the available counselling services when they expressed interest in receiving counselling. This information was also stated in

their informed consent forms. Participants were ensured that their confidentiality would be respected and that future interactions at the Radiation Oncology Unit would not be jeopardised in any way should they have chosen to leave the study.

3.8.1 Confidentiality. Participants were required to provide informed consent prior to any interviews being conducted. This signed document ensures confidentiality. Their identity remains private with pseudonyms being used for all correspondence, documentation such as transcriptions, the thematic analyses thereof, and the resultant report. At no point were their personal identities or particulars made available to anyone else. The manner in which the data was stored also ensured their confidentiality.

3.8.2 Data storage. The voice recordings of all interviews were stored on my private secure laptop. As soon as recordings were transferred onto the laptop, they were deleted from the recording device. All transcriptions and documents pertaining to data analysis were kept on the same secure laptop under a password protected folder. Only myself and my supervisors had access to these documents and recordings. After 5 years, all data shall be deleted.

3.8.3 Amendments to the research protocol. It should be noted that amendments were made to the original research protocol as difficulties were encountered with regards to participant recruitment. These amendments were approved by the Health Research Ethics Committee of Stellenbosch University.

Both the location of interviews and the criteria stipulating that participants should have concluded treatment within the last 6 months were amended to add that participants could be interviewed at their own homes, and that they could be included in the study up to 18 months after treatment. The motivation behind making these amendments is discussed in the following section relating to the limitations in the research protocols. The decision was made, after consulting with my supervisors, to maintain the inclusion criteria relating to age

of participants and to rather extend the duration following treatment as age was an important factor in exploring the psychosocial experiences of these women.

Due to slow participant recruitment while being constrained by too narrow inclusion criteria, the study approval was extended by another year. A demographics form to be presented to participants was also included in the application as it was not part of the original protocol, and once approved I consulted telephonically with participants who had completed their interviews to obtain the relevant information. The approval letters pertaining to the extension of the project (please refer to Appendix G), and the amendments and additions to the research protocol (please refer to Appendix H) have been included at the end of this thesis.

3.9 Limitations in the Research Protocol

As previously indicated, the original inclusion criteria for the study were too narrow and the proposed venue for conducting interviews limited participant recruitment. The number of women who fell between the ages of 18 and 50, and who completed curative treatment for cervical cancer within the previous 9 months was inadequate for me to reach data saturation. Despite attending weekly clinics, only five participants were interviewed during the first 9 months. Two main issues arose during this period. Firstly, there were a limited number of women who met the inclusion criteria due to the age restrictions. The majority of patients were over 50 years of age, and those that were younger often did not attend the clinic as scheduled. Secondly, women were limited in that they were unable to attend interviews at Tygerberg.

The venue proved to be restrictive in that many participants, perhaps due to their younger age demographic, were employed fulltime and could not attend meetings at Tygerberg during working hours. Amending the research protocol to allow me to conduct

interviews at participants private residences alleviated this issue, and more interviews could be conducted at the participant's convenience.

3.10 Conclusion

In this chapter I discussed the methodology of this study, including the procedures that were followed in order to recruit participants, conduct interviews, and analyse the data that was available. I also reflected on the factors which influenced my position within this study and identified the limitations which I encountered in the research procedures. The next chapter contains the findings of this study.

Chapter 4

Results

In this chapter, I will disclose the demographic details of the 15 study participants. I will then describe the five themes which emerged during data analysis: (i) the disease, diagnosis and treatments factors experienced by participants; (ii) the knowledge, communication and stigma associated with cervical cancer; (iii) the choice regarding whether to disclosure the diagnosis; (v) the psychological and emotional experiences of these women, and (v) the influential interpersonal relationships considered to be important by women in this study.

4.1 Demographic Characteristics of Participants

The study consisted of 15 participants ranging from 28 to 49 years old, with a mean age of 38.47, and who were diagnosed with either stage II or stage III cervical cancer. Majority of participants were diagnosed with stage IIb (n=10). As a prerequisite to partake in the study women had to demonstrate strong communication skills in either English or Afrikaans, but this did not limit participation or exclude those who spoke another language as their home or primary language. Of the 15 participants, five reported that Xhosa was their primary language but could speak and understand English or Afrikaans adequately enough to be interviewed. Close to half of the women were under the age of 40 at the time of being interviewed (n=7), while eight fell into the age bracket accounting for those in their 40's.

Majority of participants were unmarried (n=9), and had biological children of their own (n=13). The ages of the children varied greatly with one participant having a child of only a few months old at the time of the interview to participants who had adult children. Regardless of the age of the children, most women (n=10) indicated that their children still lived with them. Only three women indicated that they did not live with their children despite them being of a young age; these women explained that their children were being raised by

responsible family members as they as mothers were required to work or seek better employment far from home.

The living situation of the women also varied greatly in terms of who they shared a living environment with. The majority of the women indicated that they lived with other adults as well as children (n=9); partners/husbands, parents and own children usually account for those living with them. Household incomes were also reported by the women, but these were only estimations. Four women disclosed that their household income was greater than R15 000 a month; all of these women were employed full time with three having their own/family businesses. However, the majority participants (n=8) reported a household income of less than R5000 a month.

Six of the 15 women indicated that they were unemployed at the time of the interviews. For some, they had been unemployed prior to their diagnosis, and for others (n=3) their unemployment was a result of their condition and residual treatment effects such as fatigue. Of the other nine women, 7 indicated that they were employed either full time (n=6) or part time (n=1). Various levels of education were also described by the women. The majority of the women indicated that they had attended high school (n=10), but only five had successfully completed their matric year. Over and above this, another four women reported that they attended university or college, with three of them successfully graduating with a degree or diploma. I obtained the above-mentioned demographic details from the interviews conducted as well as the information obtained from the demographic questionnaires which are summarised in table 1 below.

Table 1: Summary of participant demographic details

Description	Number
Age (years)	
20-29	2
30-39	5
40-49	8
Race	
African	5
Coloured	7
White	3
Cervical cancer stage at diagnosis	
IIa	3
IIb	10
IIIa	2
Relationship status	
Unmarried	9
(unmarried but in a relationship)	7
Married	4
Widowed	2
Number of children	
0	2
1	3
2	7
3	1
4	2
Living situation	
Live alone	1
With other adults	4
With other adults and children	9
With children	1
Language (home/first language)	
Afrikaans	8
English	2

Xhosa	5
Education	
Graduated from university/college	3
Attended university	1
Graduated from high school	5
Attended high school	5
Graduated from primary school	1
Employment	
Unemployed	6
Employed full time	6
Employed part time	1
Student	1
Homemaker	1
Household income (rand)	
> 15 000	4
10 001 – 15 000	2
5001 – 10 000	0
2500 – 5000	4
< 2500	4
Unsure	1

In the following section of this chapter I describe the five themes that emerged during the analysis of the 15 transcribed interviews. An overview of the themes and subthemes, as well as the various topics that emerged from the subthemes I will discuss are illustrated in the following thematic diagram (figure 2).

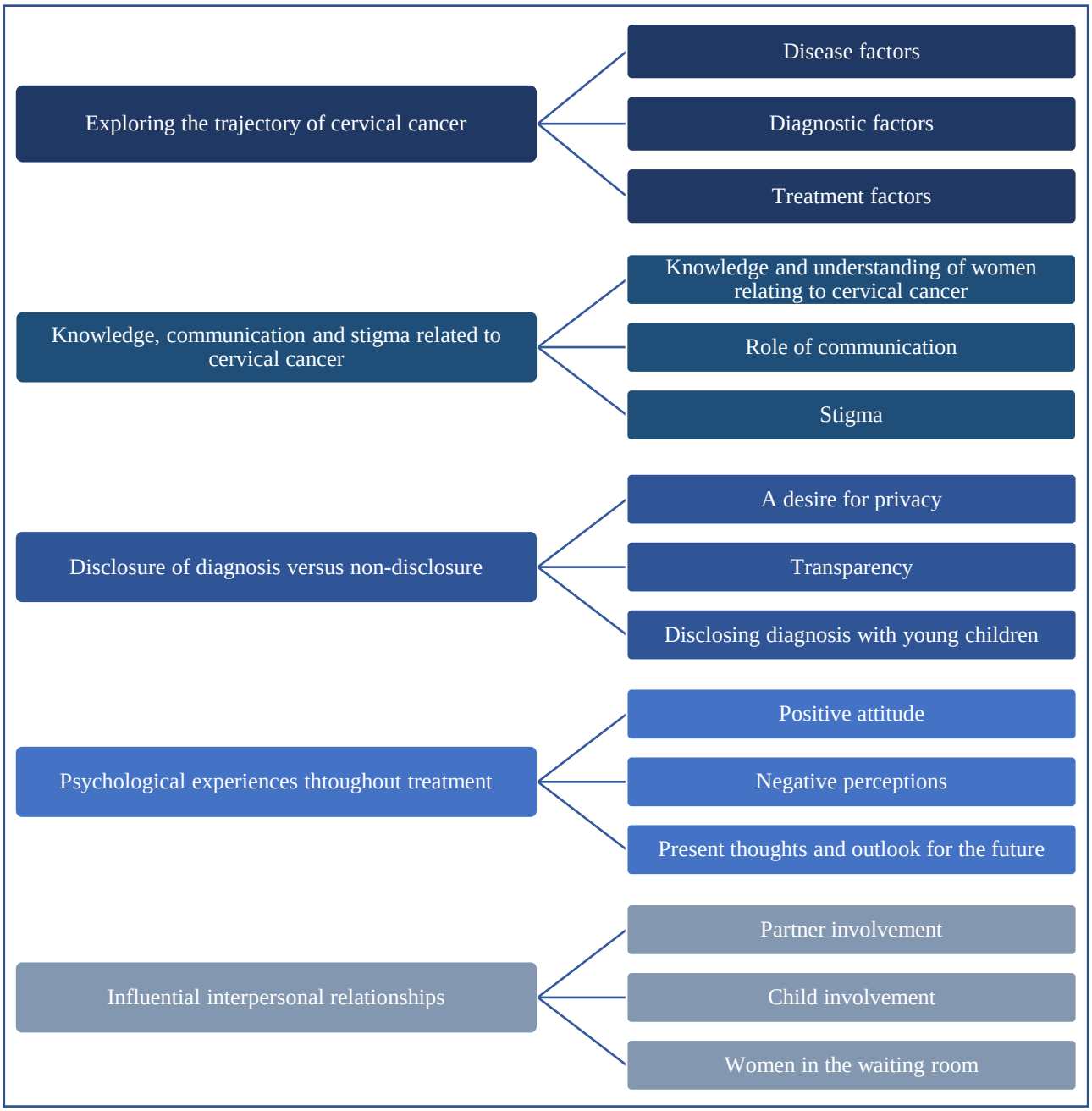

Figure 2: Thematic diagram illustrating themes and subthemes

4.2 Disease, Diagnosis and Treatment Factors: Exploring the Trajectory of Cervical Cancer

In order to discuss women's experiences of cervical cancer it is imperative to first establish the physical experiences of the disease, how women experienced the diagnostic procedure as well as symptoms that arose during the treatment process. This allows for a

deeper understanding and conceptualisation of the psychosocial impact on the participants. The participants of this study revealed unique and diverse experiences, along with certain commonalities which I report below as the first theme revealed in the analysis of the interviews conducted.

4.2.1 Disease factors. Disease factors include both the symptoms that women experienced prior to a positive diagnosis of cervical cancer, and the manner in which certain symptoms were interpreted as being associated with other health issues.

4.2.1.1 A description of symptoms. Participants reported varying degrees of severity and duration of symptoms extending from no identifiable symptoms to debilitating experiences. In some cases, the symptoms were ignored, and persisted for more than a year. Prior to seeking medical care, women reported symptoms such as fatigue, bleeding, pain, and most significantly pain and abnormal bleeding associated with intercourse.

4.2.1.1.1 Fatigue. Varying combinations of cervical cancer symptoms were reported during this study. Certain participants reported that fatigue and a feeling of powerlessness overshadowed the more common symptoms associated with cervical cancer. This indicated that each woman had unique experiences and interpretations of what symptoms where present or persistent, and the severity thereof. When asked about what physical symptoms were experienced prior to being diagnosed with cervical cancer, Eva, a 45-year-old mother of one, described her symptoms as follows:

> *"Really, it's just tiredness and…fatigue and then the bleeding… that's all, that's how I say powerless, I'm not in the mood, I get tired quickly and the bleeding is all…there was no pain and stuff like that…"* (translated)

Women reported feeling tired and a lack of energy before they were diagnosed. This fatigue was ultimately severe enough to register as abnormal due to it affecting their daily lives in a negative way. Several participants reported that they could not perform normal

tasks such as cleaning without needing to rest. This resulted in confusion and the recognition that they were not functioning as per usual.

> *"…before I found out, I was really tired. Hmm, go to sleep a lot and stuff, I could never understand what was going on and stuff, until I found out I had cancer."* (Nina, a 43-year-old mother of two diagnosed with stage III cervical cancer) (translated)

4.2.1.1.2 Pain. Pain experienced prior to being diagnosed was commonly reported by the women participating in this study. They reported that it was localised around their abdomens, and could be severe enough to disrupt normal life. Sleep patterns were disrupted as these women reported being so uncomfortable that they could not fall asleep or would wake up in debilitating pain. Maria, a 34-year-old mother of four, provided a description of the pain that she experienced, indicating its severity and duration:

> *"... then the pain comes like that, because it, it's like something eating in you ... such is the pain. It feels like something eating on you, then I just have leave everything to go to the clinic quickly, because, the pain is too severe… so it has always been for me."* (translated)

Pain could be persistent or intermittent, and was reported to affect daily activities such as work, relationships with partners and children, and roles in the household. The influence on interactions with partners and children were of most significance to the participants of this study. Those women who were parents disclosed that they felt distress in response to being restricted in the parental roles that they could occupy when in pain. Tasks that were previously seen as normal, such as taking care of hygiene tasks like bathing their children now required effort, if even possible. Women reported that they felt that being in constant pain and discomfort interfered with their intimate lives, moods and attitudes towards their partners. Ultimately, it created feelings of disconnection, and a lack of understanding and compassion from their partners were reported by several women.

4.2.1.1.3 Bleeding. Abnormal bleeding was the most commonly reported symptom among the 15 participants. Heavy, intermittent bleeding, the presence of large blood clots and continuous bleeding for prolonged periods of time were reported. Methods such as repeatedly changing sanitary pads were employed, and for one woman it reached the point where she could not prevent blood from running down her legs despite their use. Bleeding outside of the normal menstrual cycle was recognised as one of the first indications that something may be wrong.

> *"…I was bleeding a lot, with huge clots and on days whereby I wasn't bleeding, um, my discharge had a streak of blood. There was always blood. Ummm, like 25 days a month it was heavy bleeding with huge clots." (Nobomi, a 34-year-old mother to her son, and independent career women)*

Women reported that the bleeding was different and unusual, worse than what they had previously experienced. Some women reported that it got to the point were simple activities such as leaving the house resulted in stress and concern over leaking blood over their clothes. These women shared their concerns regarding being ostracised or embarrassed in public as prior experiences of visible blood on their clothes had resulted in them being shamed or discriminated against. One such experience was described by Sisipho, 29-year-old woman diagnosed with advanced stage cervical can cer, Sisipho was mocked by onlookers in her community when trying to use public transport as there was blood on her skirt and the diaper that she was using to manage the bleeding was visible. Ultimately, she was denied access to the taxi despite needing to be transported to hospital for a consultation.

Women reported feeling that they had no other option but to seek advice as they recognised that the heavy bleeding that they were experiencing was abnormal and having a negative impact on their daily lives. In many cases, this abnormal bleeding was the symptom

that ultimately lead to a diagnosis of cervical cancer. The bleeding itself, and the distress experienced by these women as a result thereof, motivated women to seek medical attention.

> *"If I didn't bleed, I would never have known ... I would most probably have died from the cancer, and I wouldn't even have known."* (Nina) (translated)

4.2.1.1.4 Pain and bleeding during intercourse. Tasha, a 28-year-old widow and mother of two (aged five and seven), disclosed that the most significant symptom which she experienced, and what ultimately led her to demonstrate health seeking behaviour in terms of approaching medical professionals, was pain and bleeding during intercourse with her partner. Bleeding after intercourse was likened to that of a nose bleed, covering the sheets and bedding. This experience was echoed by several women in the study, including Michelle, a 43-year-old women diagnosed with stage II cervical cancer, who stated the following:

> *"… when my boyfriend and I were intimate, I was bleeding…so that raised alarm bells, but I left it, this was a few months, you know it was going on like this, and hmm, I thought well it was just a little bit, it's not hectic, hmm, you know I'll go in for a Pap smear."*

A commonality among the participants was that they were reluctant to discuss pain and bleeding as a result of intercourse outside of the clinical setting. Unfortunately, pain and heavy bleeding were often associated with the fluctuations of a woman's menstrual cycle, resulting in symptoms often being misattributed to non-cancerous origins. Women reported that when they expressed concern regarding their symptoms to family, friends or even healthcare workers, they were often met with advice relating to pain management and hormonal interventions such as birth control to regulate their cycles.

4.2.1.2 Conditions mistakenly associated with the symptoms. As stated above, several women in this study indicated that they associated their symptoms (specifically bleeding and abdominal pain) with their menstrual cycle or hormonal abnormalities due to

menopause. Especially at the onset of symptoms, where they were not as severe as later reported, participants disclosed that they assumed it was a severe period. Only once the symptoms persisted or worsened did they seek medical care. In the case of Fundiswa, a 30-year-old single mother of three, she recognised that her menstruation was persistently abnormal.

> *"It was March and then I experienced I was on my periods…I go to my periods and then after that, I used to go three days mos, and then I go four, four, it's the fourth day now, fifth, six, haebo, it's been a week now I'm on my periods…"*

Unfortunately, the advice that she sought from a friend led to her taking medication which stopped the pain and bleeding, masking her symptoms and further delaying her diagnosis. Women reported that falsely believing that their symptoms were due to alternative conditions commonly prevented them from health-seeking behaviour.

One specific case worth noting is that of Felicia, who was in her third trimester of pregnancy when she was diagnosed. Felicia, a 30-year-old mother of four, described how at first, she mistook bleeding for her miscarrying during the earlier parts of her pregnancy. It was only when pain accompanied the bleeding during the later stages of her pregnancy that she sought medical care as she feared that she was going into labour.

> *"At night I can't sleep, then I sit in pain here, I sat here one night, I'll never forget that day, one Friday night while my husband slept, then I couldn't sleep from the pain, it looks like the baby wants to come out anytime soon."* (translated)

In most of the cases described by women during this study, severe symptoms were the driving force behind seeking medical care and obtaining a diagnosis of cervical cancer. Although certain symptoms, such as fatigue, abnormal bleeding and pain, are commonly indicated, the experiences were unique for each woman.

4.2.2 Diagnostic factors. Diagnostic factors refer to the experiences of women during the diagnosis process. Women described various means of being diagnosed with cervical cancer, as well as diverse reactions to their diagnosis. Several reported going for routine Pap smears which later revealed abnormalities, while one stated that it was during surgery for a cyst on her ovary that a malignant tumour was identified. Under diagnostic factors I will briefly describe the means by which the participants of this study were diagnosed, where after I will focus on women's reactions to their diagnosis from a personal perspective.

4.2.2.1 Diagnostic process. Just as the presenting symptoms were unique to each participant, so was the diagnostic process. The primary means of diagnosis was through a Pap smear. One woman reported attending a Pap smear opportunistically, attending a prevention drive at the hospital where she was being tended to for another condition. Most of the other women indicated that they were urged to have one performed in response to their symptoms. Such participants were either referred to the clinic as a doctor observed something abnormal upon a physical examination of their cervix, or the doctor performed the Pap smear themselves, notified the participant of the results and referred them for further treatment.

In cases where a lesion or tumour were visible under scan or physical examination, women reported that a biopsy was taken for testing. This process is often described as painful and uncomfortable. Tasha described how following the rupturing of an ovarian cyst, doctors identified what they suspected to be a fibroid myoma. This fibroid later proved to be a cancerous tumour following a biopsy. Jean, a 34-year-old married mother of two, reported that something abnormal was clearly visible to her doctor upon internal examination, which motivated him to do a biopsy immediately. She received her results shortly thereafter, and described her experiences as follows:

> *"... something is unusual, so he is going to scrape it off and send it away, but he can almost certainly say it is cervical cancer ... I took it, and he scraped it and sent it*

away, so 4 days after that, then I got my results, it was positive, cervical cancer. " (translated)

Although the diagnostic process may have been simple in that a Pap smear or biopsy accurately identified cervical cancer cells for most women, that was not the case for all of the participants. Three of the 15 participants indicated that they had received Pap smear results which did not indicate any abnormality thereby delaying the diagnostic process. When enquiring with Sonja about whether she had attended a consultation and Pap smear previously with regards to her symptoms, she had this to say:

"… I did, if they referred me to a Pap smear, then every two or three years I got a Pap smear. But there has never been anything to let them say there is a cancer present or something." (translated)

Sonja was one of three women who indicated that their Pap smears did not show a precancerous cells. A normal Pap smear for these women led to a delay in the diagnosis of cervical cancer and a resultant progression of their disease. Frustration and disbelief were evident in that these women expressed dismay at not being diagnosed earlier.

4.2.2.2 Reactions to cervical cancer diagnosis. For the purpose of the discussion related to this theme only the reaction of the women, and not those of their support networks will be discussed here. Upon confirmation that they had cervical cancer, the women unanimously revealed shock and surprise. Even those who suspected that cancer was a potential diagnosis were not emotionally prepared to receive such a diagnosis. Denial played an important role as most women indicated that they couldn't believe it was happening to them. Michelle particularly demonstrated shock as she attended for a screening opportunity for a Pap smear, not demonstrating identifiable symptoms beforehand.

"Ja, in denial, it's like this, can't happen to me you know, I've been through, you know cause I've had a, quite a hectic life so, I thought one more thing, I can't deal

with this, it's just it's, it's gonna push me over the edge, hmm, and and then you know the days just go on and you just deal with it day by day by day."

For all but one woman, who reported being calm and optimistic, the immediate response was negative. Feelings of anger, shame, confusion, uncertainty, being overwhelmed, fear and hopelessness often arose. The women revealed that they were generally emotional and distressed in response to the news, and did not know what the future held for them. It appeared as though an overarching fear of not being able to overcome cancer and its treatment informed much of the responses.

"You are afraid of the prospect, what is going to happen to you, what is actually, because you honestly do not know what the situation in your body is. Then, then I felt, I'm probably going to die sometime. But it was not meant to be so…" (Sonja) (translated)

Those participants who were mothers indicated that their reaction to their own diagnosis was immediately directed to their children. The fatalistic ideas relating to cancer and it being a death sentence forced them to consider the well-being of their children. Again, women demonstrated that the well-being of others took preference over their own health. This concern for her children was voiced by Nina who stated the following when asked what she thought of when receiving her diagnosis:

"... my children, first worried about my children, what is going to happen if I have to get worse now, much worse, hmm, what is going to become of my children and things ..." (translated)

As is evident, the reactions of participants varied greatly. Yet, disbelief and shock dominated women's thinking at this time, as well as concern for their immediate families.

4.2.3 Treatment factors. The women undergoing treatment for cervical cancer at Tygerberg Hospital reported that they underwent surgery (most commonly a hysterectomy),

chemotherapy or radiation, or a combination of the above. Section 4.1 elaborated on which patients received which treatment. The most common combination was alternating chemotherapy and radiation (both internal and external). Most women described these treatments as difficult to endure due to the new physical symptoms that arose such as fatigue, pain, nausea, diarrhoea, and even anxiety and depressive mood. Despite the severity of symptoms, the women ultimately indicated that it was bearable knowing that they were being healed of the cancer in their bodies. Participants were either treated as outpatients, travelling to the hospital daily, or as inpatients. Two main subthemes emerged from this theme relating to treatment experience; firstly, communication and positive interactions with healthcare providers improve the overall treatment experience and secondly, that disruptions to daily life were evident.

4.2.3.1 Communication and interactions with healthcare providers. Those who described adequate communication and pleasant interactions with healthcare providers described better experiences in terms of their treatment and how they framed their experience than those women who had negative experiences in terms of communication, support and sympathy. Most women reported positive experiences with the various healthcare providers they encountered, as evidenced by this quote from Nobomi:

> *"You know, every time I'm thankful. I would always include the doctors, the nurses, the radiographers...is that what they're called? ...of Tygerberg Hospital. They were very helpful. They were very professional. They were caring. They were supportive. I cannot fault them at all. Each and every one of them, from the day I first went there, to my hospital stays, to my treatment…"*

The women reported that they felt that they received adequate information about the treatment that they were going to receive, with medical professionals explaining procedures and what to expect consequently. This laid to rest many of the negative perceptions that they

had of chemotherapy and radiation. When indicating to the healthcare professionals that they were unsure of treatment procedures, women were met with not only information but also a caring attitude. This is evidenced by how Elsabe, a 40-year-old mother of two diagnosed with stage II cervical cancer, describes her experience during the initial stages of chemotherapy when she was unaware of what to expect:

> *"They explained to me that one sachet is the salt water one which is to cleanse your blood, one is for nausea and then it is chemo then again to rinse the veins a bit. It will take about two to three hours. Then I said oh ok, and they give you a blanket for if you get cold, they are on top of things, and they care about you as a person."* (translated)

Those who reported anxiety and fear during treatment also indicated that they were unsure of what to expect. This uncertainty appeared to worsen the experience and foster anxiety. Those participants who required/desired more information about procedures from healthcare providers reported more fear during treatment. It should be noted though that women who obtained information and support from their healthcare providers demonstrated a desire to know more about their condition and what to expect from treatment, appeared to ask questions and were generally more open to communication and interacting with others. Alternatively, those who indicated uncertainty and negative interactions often also reported during their interviews that they wished for privacy and were in denial about their condition. They adopted an 'ignorance is bliss' approach in that they did not want to ask questions or engage with their healthcare providers in fear of receiving more daunting information.

4.2.3.2 Disruptions to daily life during treatment. Women reported disruptions to their work lives, personal lives and involvement in daily activities such as household chores during treatment mainly due to exhaustion. The most commonly reported concern was related to not being able to go to work, or not being able to perform adequately when there. Felicia described how her work required physical strength and manual labour, which she was not

strong enough to perform. Even when at home resting during treatment, household tasks proved to be too demanding:

> *"Yes, I clean but hhh, if I work very fast then I get tired. And then I tremble, I don't know why I'm trembling. If I walk too fast too. "* (translated)

In this theme I described what women experienced during the trajectory of cervical cancer from the symptoms they experienced which spurred them on to seek medical attention to the treatment they received. I elaborated on these women's reactions to their diagnosis, as well their experiences relating to interactions with healthcare providers and effect on daily life which influenced their outlook during treatment.

4.3 Knowledge, Communication and Stigma Related to Cervical Cancer

Every participant in this study indicated at the onset of their respective interviews that they had little or no understanding or knowledge of cervical cancer prior to their diagnosis. The younger women in the study shared surprise at their diagnosis as they assumed that they were too young for cancer. This idea was explained by the notion that only older people get cancer. Although limited knowledge was evident, it soon became apparent that each woman did have some degree of knowledge of the disease, often influenced by the stigmatic notions which surround cervical cancer and cancer as a broader term.

4.3.1 Knowledge and understanding of women relating to cervical cancer. Lack of knowledge or understanding is evident in how women failed to recognise the symptoms of the disease or misattributed them to other conditions such as menstrual pains/bleeding or menopause. Many women demonstrated disbelief at their diagnosis, expressing confusion around how it could have happened to them. A lack of knowledge surrounding cervical cancer, its causes and its symptoms was blatantly apparent.

4.3.1.1 Lack of knowledge relating to the disease. The women in this study reported that they had limited or no knowledge of cervical cancer prior to being diagnosed with the disease. They may have heard of it, but they knew little beyond the name.

> *"I heard about it, but I never knew what it meant, and I never knew where it occurred and how it occurred, and, what are its symptoms or anything like that ..." (Karen, a 49-year-old mother of two, diagnosed with stage II cervical cancer)* (translated)

A major gap in knowledge is evident in relation to the specific cancer (cervical cancer), with women reporting only the broadest knowledge and awareness of cancer in general. They may have acknowledged knowing about breast cancer and 'womb cancer', but that was where it typically ended. The only information which they associated with cancer was the label of it being a death sentence, even though that assumption is often incorrect and discouraging. Eva described how she only knew of cancer in the broadest sense:

> *"In fact, I didn't know anything, I just knew cancer was cancer I didn't even know there were different types of cancer ... to me, cancer was cancer and, to me, it was like a big story because, obviously when you hear that cancer name, then you think you're dying… "* (translated)

Much of the knowledge that women possessed was based on what they knew of other cancers, and what they had witnessed within their families. Most participants reported that they had known someone in their family who had passed away of cancer, whether it be a parent, sibling, or distant family member. For those who claimed to have had some knowledge, they admitted that it was limited and only applied to the broadest concepts of cervical cancer such as the location of the cancerous lesions and the feared chemotherapy or radiation treatment options. The sources of information varied, but there was an indication that women encountered relevant information by chance. Michelle indicated that what she knew about cervical cancer prior to her diagnosis was purely based on a magazine article

which she had once read. It was a chance encounter with a prevention drive that gave her the opportunity to receive a Pap smear.

Despite being familiar with the term ‘cancer’ or ‘cervical cancer’, women’s understanding and knowledge relating to the cause and prognosis of the disease was predominantly shrouded in misunderstandings, ignorance, fear and stigmatic ideas propagated by those in their communities or families who shared a lack of knowledge.

4.3.1.2 Knowledge of Pap smears and prevention efforts. The women of this study reported that they were aware of Pap smears, but when questioned with regards to what a Pap smear’s intended purpose was, most could not demonstrate any significant insight. Only two women knew that Pap smears were utilised for identifying precancerous lesions, and both of these women requested Pap smears in response to their symptoms. Other women provided vague descriptions relating to Pap smears being a test that women just have to do. Tasha reported similar sentiments, but indicated that she had questioned what its intended purpose was. Her curiosity was not enough for her to actually pursue the relevant information though, and it was only after her diagnosis that she received the answers to her questions.

> *“I don't think people know about cervical cancer or why it is they go for a Pap smear, same as me. I didn't know why I go. I just know after my kids; you have to go for a Pap smear. And that was it, you know? But why? What is so significant of going to a gynae and having a pap smear, you know?”*

Due to a lack of knowledge relating to Pap smears and related prevention efforts, women reported that they were not motivated to seek such care. In fact, several women reported never having been for a Pap smear as they had no symptoms which they thought necessitated it. Not understanding the purpose of a Pap smear, to identify precancerous cells before they necessitate more invasive interventions after progressing to cervical cancer, indicates a lack of understanding pertaining to the progression of the disease. My interactions

with these women and the information they revealed indicated that they were exposed to information regarding Pap smears, however insufficient consolidation of this information which they were most likely exposed to was evident as they acknowledged knowing that they should go for regular Pap smears as part of health seeking behaviour.

4.3.1.3 Perceived cause of cervical cancer. The strongest assumption among all of the participants was that their cervical cancer should have some hereditary cause. All had heard of other cancers, and were aware of its prevalence even within their families. Those who had familiar cancer experiences suggested that they felt it was inevitable that they should one day be diagnosed with cancer of some form. These assumptions were logical for those who had a close family member who had previously been diagnosed with cancer, but there were also women in the study who had no familial history of cancer. These women sought other explanations relating to other behaviours such as smoking or sexual activity, perhaps due to associating the cervix with female sexual organs.

A few women reported that they believed cervical cancer may have a sexual origin, yet did not communicate knowledge of HPV or a viral influence. There was much uncertainty in descriptions as none wanted to admit that they agreed with this theory. They were acknowledging information which they had heard at some point. This is exemplified by Eva:

> *"I don't know where it comes from anyway, maybe it's hhhh, a transmission of sexual or of sex or what, I have no idea …"* (translated)

For those women who had only had one sexual partner in their lives (usually their husband), they sought other explanations. Jean was one such woman.

> *"… I never knew where it came from, or what the causes could be. … The one girl here from Robertson, she's also married and, there was never before anyone else in their marriage, so, what she told me, too, it's stress, and such little things."* (translated)

4.3.1.4 Ignorance is bliss versus knowledge is power. Some participants reported that they preferred to remain ignorant of all information relating to their conditions as for them gained insight contributed to anticipation and fear. On the other hand, certain women preferred to be equipped with knowledge as they felt they knew what to expect. Knowing what to expect in terms of both disease and treatment factors countered the fear that previously developed in response to the unknown.

Three women indicated that it was better to not have too much information. Nina provided the following rationale for her approach:

> *"Yeah I know a little bit about what's going on and stuff… don't want to chase too many ghosts because I feel it makes you more paranoid and stuff, I just want to know enough that I know what the situation is about and, hmm, a be a little open minded that it will not be cured overnight and stuff ... "* (translated)

Karen voiced the same reasoning, but did so in hindsight after 'googling' her condition. After being proactive she wished that she could 'unsee' what she had found. Contrary to these attitudes, other women indicated that more knowledge made them feel empowered and less fearful. It was apparent that a lack of knowledge fostered fear in these women, which could be countered by seeking information from sources such as healthcare providers. This attitude was particularly strong during treatment for these women as knowing what to expect during chemotherapy and radiation served as a comfort. They understood that there was nothing to fear from the machinery or medication as per the explanation that they were given by their healthcare practitioners:

> *"She explained to me, held my hand… I was very comfortable. People have always asked me why do you look so comfortable, I say because there's nothing that scares you in there..."* (Eva) (translated)

4.3.1.5 Motivation to gain knowledge and awareness. Motivation to learn about the condition was apparent in those women who reported that knowledge resulted in diminished fear and uncertainty. A desire to know more was spurred on by an internal drive to improve their own lifestyle and to protect their children by facilitating healthy choices and understanding about cervical cancer. For those wanting to live healthier lives, to take better care of themselves to prevent a recurrence of their cancer, often self-directed learning served as a source of information. Karen described how she wished she had more information during her time in treatment about how she could have made changes to improve her lifestyle at home. As a result, she (like many other women interviewed) used social media and the internet to learn about their conditions and how they could better take care of themselves in terms of diet and exercise.

The impression given by participants who had children was that wanting to protect their children and to equip them with knowledge and understanding was the biggest driving force behind their desire to learn about the disease. They reported that they wanted their children to be able to avoid the same fate by being better informed, and as such mothers need to have the relevant information to convey to them. Sonja explains her motivation to know more:

> *"…so that I can see the kids can escape it if they could or if they can, I mean so I would have liked it to be, to have more information now, for me it's so important to have more information about cervical cancer."* (translated)

These women indicated that they wanted to equip their children with the awareness that would help them to prevent contracting HPV and developing cervical cancer. With the relevant knowledge, they would be able to communicate more effectively to facilitate knowledge formation. From the interviews it is apparent that more relevant knowledge and

understanding of cervical cancer, its cause, prevention and diagnosis, is desired to equip women to better care for themselves and those close to them.

4.3.2 Role of communication. Women reported varying levels of comfort with communicating about their journeys with cervical cancer. Some were open to disclosing their diagnosis with others, but most were resistant to share this information with individuals outside of their immediate family or support systems. Communication with family members, especially partners and children, is important as they are a prominent fixture in the patient's daily life and an integral source of support. The main subthemes that emerged relating to communication was a lack of communication, the existence of misinformation which was communicated by assumed to be trusted sources, and a desire to share information following treatment to raise awareness.

4.3.2.1 Lack of communication. The women interviewed for this study indicated that cervical cancer was not a topic of conversation. This sentiment was echoed by most of the women in the study. Even those who acknowledged that they did not have a problem with sharing their stories admitted that speaking about cervical cancer was not the norm, and at times was actively avoided by both themselves and those in their communities.

> *"And with the cervical cancer, not many women talk about it and stuff, they're not going to admit openly, they're not like me now, they're not going to openly admit they have cervical cancer ..."* (Nina) (translated)

It was revealed that participants were aware of their own resistance to discussing the topic, and questions were raised relating to what motivated women who have cervical cancer to resist disclosing their diagnosis and sharing their journeys with others. This lack of disclosure by women who have had the disease, even though they are experienced in the trajectory of the disease, may contribute to the negative impression and misleading information that is left to flourish about cervical cancer in the public.

4.3.2.2 Misinformation. Several women in this study encountered incorrect or misleading information at some point during their journey pertaining to the cause of their symptoms and the cause of cervical cancer. The sources of this information ranged from family members and leaders in their communities, to the healthcare providers that they consulted with prior to being diagnosed. For three women in particular, the incorrect guidance they received from online sources and healthcare professionals at their local clinics influenced the time it took to pursue healthcare relating to their symptoms and ultimately a diagnosis.

Nobomi gleaned from online sources that her contraceptives could influence her hormones, resulting in the heavy bleeding and pains which she was experiencing, for more than 12 months. With this information she assumed that the contraceptive injection was the cause of her symptoms, delaying her from seeking further medical attention for almost a year.

Felicia and Fundiswa received misleading information from healthcare practitioners once their Pap smears indicated cancerous cells. Felicia received input from the local healthcare practitioner whom she approached before being referred to hospital. Without a proper diagnosis of cervical cancer and the corresponding stage, Felicia was informed that should she have stage three cervical cancer it would be impossible to stop its progression. Such information, which may be both misleading and distressing in a time where the patient does not have a confirmed diagnosis, provokes fear and uncertainty. Despite trusting their healthcare providers to provide accurate and reliable information, even the nurses that Fundiswa encountered propagated information influenced by their own prejudices and stigmatic ideas, which may not necessarily have been based on facts.

"…they were talking about consequences of doing abortion, they said it could lead you to cancer, you can have cancer, there is a possibility that you may have cancer

when you. Ja they said they, if you do abortion, the consequences, you can have cancer…" (Fundiswa)

The most prevalent input related to contraceptive use causing the experienced symptoms, leading to misinterpretation on behalf of the participant. Further, the most distressing inputs related to the treatability of cervical cancer and the cause being attributed to actions of the women themselves. These women reported that misleading information not only delayed their diagnostic process, but also contributed to feelings of confusion, fear and even shame. Ultimately, a lack of knowledge and awareness, often fuelled by incorrect information, led to distress and resistance in sharing their journey. Interestingly, despite these feelings, all of the women indicated that it was imperative to get important and accurate information about cervical cancer across to women in their communities.

4.3.2.3 Propagating information. Gaining knowledge and insight is particularly important in the pursuit of propagating correct information which could influence the well-being of those surrounding these women. Of particular importance to the women in this study who had daughters, was the ability to effectively communicate accurate information which would help their daughters to protect themselves against cervical cancer in the future. The main objective was to provide insight into what the disease is, how their daughters could protect themselves against HPV by practising safe sex, to be aware and not resistant to utilising preventative measures in the form of vaccines and Pap smears, and how to recognise the disease in its early stages. When asked about what she would share with her daughters, Maria had the following to say:

"I will tell them how it started for me and, when they reach the age to do a pap smear... then they should go for a pap smear regularly." (translated)

Propagating information through communication was an important concept for many of the women. They demonstrated a desire to help those surrounding them by equipping them

with information which will raise awareness and screening practices. Participants stated that they wanted to share what they learnt from their own experiences with the disease and from those who have assisted them along the way, as voiced by Elsabe who felt empowered by the information she received during treatment:

> *"I feel I got enough … now I can, I can talk about myself now, and I can talk about my experience and everything and I can maybe, give a little more information if they don't know now because I know more now…"* (translated)

A desire to challenge the preconceived ideas surrounding cervical cancer which women are faced with on a daily basis was evident in this study. Through communicating effectively, sharing their experiences and countering the incorrect information which is prevalent in our communities, these women hoped to challenge the stigma surrounding cervical cancer which influenced their well-being throughout their journeys.

4.3.3 Stigma. When first enquiring about the stigma that women experienced during their journey with cervical cancer, women were resistant to disclose any experiences. In fact, they indicated that they had no prior knowledge of cervical cancer itself (as was reported on earlier) and as such were not aware of any negative perceptions associated with the disease apart from the association of cancer with death. However, as the interviews continued, several preconceived ideas and negative perceptions and experiences were revealed. One woman even described cervical cancer as a "skande" (translated: scandal), alluding to the perception that it is associated with promiscuity (Anna, a 36-year-old single mother of one child). Three common feelings and beliefs relating to stigma were reported by women. These included the belief that promiscuity results in cervical cancer, that the disease can be carried over from one person to the next, and a resistance to disclose information about their journeys with the disease due to discouragement and shame.

4.3.3.1 'Promiscuity leads to cervical cancer'. Only two women indicated that they believed cervical cancer had any relation to sexual activity, yet several women revealed encountering stigmatising ideas suggesting a link between promiscuity and cervical cancer. They either voiced these concerns themselves or described experiences with other women in their communities who voiced these ideas. Nobomi described the scenario that she encountered upon sharing her diagnosis with a close friend:

> *"I remember telling this other friend of mine that I have cancer... she asked what cancer I have...so I said cervical. So, she was like, it can only mean you were sleeping around. You know... And then I really believed that, I really did believe that maybe I had slept with the wrong people in my past? Maybe that's why I am like this."*

Many women in this study had similar experiences with those who were meant to be a source of support propagating such ideas which led participants to describe feelings of shame and confusion. Shame in particular was a driving force behind further concealment of experiences and contributed to isolation and seeking privacy. The women also reported that people placed responsibility on the shoulders of the female; the woman was always communicated to be the promiscuous one. Open communication was thus supressed as women did not want to perceived to be promiscuous, a fear of being judged was prevalent and led participants to question their own actions. For the interviewee who had only ever had one sexual partner, this proved to be particularly frustrating, but it did spur on resistance in that they could confidently discredit the stigma suggesting promiscuity.

4.3.3.2 'Cervical cancer is contagious'. Women reported that their initial reaction to their diagnosis was to believe that they were 'unclean', 'diseased' and 'contagious', to put in their own words. Although they did not indicate a source other than themselves for these ideas, these conceptualisations were echoed by several women which may indicate that a stigma surrounding the spread of cervical cancer does exist. As with the stigma surrounding

promiscuity, the fear of carrying over this disease through contact caused women to resist interactions with others. Maria put to words what others were not able:

> *"... I thought, oh, I'm not going to have any friends anymore, and so, because it's sickness, and for me it was almost like, now it's a contagious disease that I have and hmm. I thought about all these things because I, I was embarrassed because, it almost felt like it was a contagious disease..."* (translated)

The above-mentioned stigma which women encountered served to foster shame and fear in the participants, which led to isolation and limited their support during a time when it was most necessary. Women reported that they felt that they were unable to share their experiences with others as they feared rejection and discouragement.

4.3.3.3 Resistance to share journey due to discouragement and shame. Stigma itself might not have been discussed or identified but its effect was evident in women's resistance to disclose their diagnosis with those outside of their immediate family. They expressed apprehension due to the discouragement they received from those assumed to be supportive. Such encounters may foster feelings of embarrassment and shame, driving women to conceal their diagnosis and further isolating themselves from potential sources of support. Nobomi divulged her sentiments with regards to sharing her diagnosis:

> *"My family and my partner, it was very easy. But speaking to other people outside of that circle, it was very difficult. I felt ashamed. I felt embarrassed. I don't know why but that's just how I felt. Yeah, I felt as if people were going to judge me for something..."*

Each woman who admitted to experiencing these ideas indicated that they felt it was important for information to be shared which could raise knowledge and understanding relating to cervical cancer in order to challenge these ideas. Despite this ideal, women reported varying degrees of willingness to disclose their diagnosis and subsequent

experiences with others. Although sharing one's diagnosis emerged frequently in the data, and in association with multiple themes, it is prevalent enough that conceptualising it as its own theme was warranted.

A lack of knowledge and understanding pertaining to cervical cancer was evident, both in terms of its cause and how it could be prevented. Each woman displayed unique perspectives on a desire to gain understanding of the disease, usually motivated by fear. Women either wanted to gain insight or avoid information in order to avoid feeling fearful. An important factor which emerged was that every participant had been exposed to stigma in one form or another. Open communication was often suppressed in response to this, yet a desire to propagate accurate information was evident as women wanted to challenge the misinformation relating to cervical cancer which they had encountered

4.4 Disclosure of Diagnosis versus Nondisclosure

According to participants, feelings of shame and a fear of judgement were the main motivators behind withholding diagnosis disclosure. Following a positive diagnosis, the women were faced with whether to disclose this information and to whom, fearing that reactions would result in scrutiny and discouragement. The women in this study revealed a broad range of attitudes and approaches towards sharing their diagnosis with loved ones; some chose to conceal the state of their health choosing to be private in order to avoid judgement and shame, while others were open and transparent. Considering these concepts, the subthemes relating to disclosure relate to a desire for privacy, transparency, and sharing the diagnosis with young children.

4.4.1 A desire for privacy. A consensus among the interviewees was that women did not resist telling their partners about their diagnosis, but choose carefully who else to reveal the information to. The main motivation behind this was that these women were sceptical of how others would react and did not want to be treated differently. For this reason, the choice

of who to share their journeys with was limited to those closest who were perceived to be the most trustworthy and invested in the well-being of the participant. After disclosing her diagnosis to a friend in the community, Eva describes her feelings as follows:

> *"... the woman asked me why didn't you tell me, then I said you get people that react differently, once you tell someone I'm so sick then you see how different people's attitudes are ..."* (translated)

The following quote echoes the same notion of resistance, exposing how Tasha feared that her concerns would be expressed by those who she would divulge her diagnosis of cervical cancer to:

> *"Because I didn't want to... because many people have this notion in the head that okay, if you do have cancer, you're going to die. The same as me, same as what I thought. So, I didn't want that, you know, so I just kept it to myself and, yeah…"*
>
> (Tasha, who only revealed her diagnosis to those family members closest to her)

Feeling out of control with regards to regulating others' reactions to their diagnosis drove a desire for privacy. Reactions from extended family, friends, community members and colleagues were hard to predict. Not knowing how someone would react to the information proved to be intimidating, perhaps due to participants feeling out of control and as if their private affairs were being exposed. As the information to be disclosed is deeply private, disclosing their diagnosis with employers and employees was particularly difficult for many women. Unfortunately, certain participants were forced to disclose their diagnosis as their behaviour or absenteeism was gaining unwanted attention. In such instances, the decision of whether to disclose their diagnosis of cervical cancer was influenced not by a desire to share, but rather a desire to avoid possible negative repercussions. Eva was unsure of how to reveal such personal information with her employer, but ultimately had to account for her absence from work during treatment.

> *"Sometimes you don't know how to talk to your work people ... and, all your illness secrets, you don't know how people are going to act towards you or what ... and then she asked me why I didn't tell her? Then I said I just didn't think it would get to that point because I just felt, my privacy and my illnesses are my illnesses, my business is not anyone else's…"* (translated)

Despite a desire for privacy, there were situations that arose for participants where they felt forced to share their diagnosis. In Eva's situation, sharing her diagnosis with her employer resulted in added social support as her employer was considerate of her situation.

4.4.2 Transparency. In contrast to the above extracts, there were three women who described how they were not resistant to disclosing information with others. This may be due to intrinsic characteristics regarding privacy. It is clear than not all women were affected equally with the burden of self-blame, rather attributing the cause of their disease to being out of their hands. These participants appeared to be less fearful of the reactions of others, did not anticipate feeling shame or embarrassment, and felt it was their responsibility to speak out. Feeling that it was not her fault that this disease had befallen, Maria had the following to say:

> *"... it's a God-sickness, I can't help it crossed my path ... I can't help it, and I'm talking about it and I'm ... giving other people advice."* (translated)

A desire to educate others and raise awareness for cervical cancer was another motivator behind women disclosing their diagnosis and experiences. Several women demonstrated this desire to disseminate information, to better equip other women to protect themselves against this disease. As mentioned in a previous theme, this desire also extending to women wanting to protect their children, but the age of the child was a determining factor for some participants.

4.4.3 Disclosing diagnosis with young children. In regards to sharing a diagnosis of cervical cancer with their children, women had mixed reactions. Some felt that transparency

was best and others felt that concealment was a better option. Those who rationalised the second approach, to avoid disclosure, argued that it was due to a desire to protect their children from worry. Again, uncertainty in the reaction of others is evident. These participants usually indicated that they felt their children were too young to understand what cancer (specifically cervical cancer) was and how to conceptualise the disease.

> *"…There was one stage I was like, oh, I need to tell my kids and sometimes I'd want to tell them. How do you explain this to them to make them understand? You... I don't think there's any way you know…"* (Tasha, who has two young children that she raises alone after their father died)

Once the diagnosis was shared with children, women reported mixed reactions. For the most part, their children reacted with fear and confusion to the word "cancer"; worried that they were going to lose their mothers. Each child reacted differently, and each participant's account of their children's reactions were unique. Mothers also managed their children's reactions differently. Children also demonstrated varying degrees of understanding, which was heavily influenced by how much information the mother disclosed to the child, and the age of the child. Elsabe, mother of two, revealed that her younger child did not understand what was wrong with her mother, and as such did not project too much concern, but her older son (7 years old) was curious and enquired about both the disease and his mother's well-being. An appropriate amount of information was shared with him in a way that he could conceptualise:

> *"He asked, what is cancer? I don't think he had a clue what it is ... and hhh, my cousin explained to him that it's just where you get sick and then you have to go to the hospital to get healthy, then I told him vaguely, she did not go into details ... and obviously he would not have understood ... "* (translated)

A common factor among those who were seemingly resistant to being transparent with their children initially was that they were unmarried or single parents. Despite initial resistance, all of the women indicated that they would share the information with their children at a later stage in their lives. They reported that a desire to protect their children from worry was overshadowed by a need to protect them against the disease later in their lives when they may be at risk; this in itself motivates them to share their experience.

"I'll tell them one day when they are older. Yeah, when they would understand, when they can understand that's why it's important, like, to go for your check-up." (Tasha)

From the interviews, and from interacting with the participants, disclosing one's diagnosis and effective communication with others is important as a means to ensure adequate social support but was inhibited by a desire for privacy in order to avoid the negative reactions of others. Interviewees either wanted to avoid the shame that came with judgement, or wanted to protect those closest to them from worry.

4.5 Psychological Experiences Throughout Cervical Cancer Treatment

The women in this study reported various reactions and attitudes upon receiving a positive diagnosis for cervical cancer. Despite initial cognitions centring on the association of cancer with death, as women underwent the treatment process their thoughts and attitudes changed for the most part. This theme focusses on the attitudes of women, whether it be positive or negative, in relation to their experiences as well as the outlook that they held for the future following successful treatment for cervical cancer.

4.5.1 Positive attitude. In spite of the difficulties faced by the women in this study, most stated that they managed to keep a positive attitude throughout treatment, motivating themselves to persevere. They openly discussed their challenges, but revealed that a positive attitude and personal coping strategies which they adopted assisted them to overcome both physical and emotional hardships during the experience of cervical cancer.

4.5.1.1 Being positive considered a tool to overcome disease. Several participants indicated that maintaining a positive mindset, no matter how difficult it was to do so, contributed to them persevering through treatment. Despite the initial shock of being diagnosed with cervical cancer, these women took the initiative to motivate themselves to push through the challenges they were presented with. Their health was a major priority for them, as well as conquering the disease. Instead of questioning why they were the ones burdened with cancer, those with a positive attitude focussed more on what was within their power, perceiving their disease and its treatment as something they simply had to go through. They viewed treatment as the means by which they could be healed, positioning it in a more positive light than those who focussed on the negative consequences and symptoms associated with it. This was exemplified by Maria who stated the following:

> *"...it's just the process you have to go through, so I don't think anyone or anything could have made it better. But the treatment I got was the best. It's just, it's really not a big thing for me to get my treatment… you have to go, it has to be done so, I still didn't feel it was a burden to me…"* (translated)

The women acknowledged that being positive and focussing on the future and efficacy of treatment helped them to ignore the negative cognitions that threatened to demotivate them. Negativity needed to be avoided as the burden of the disease would become overwhelming should negative thought dominate cognitions. Maria went so far as to say that remaining positive not only helped her to endure treatment, but assisted in healing the disease. She associated negative thoughts with worse symptoms, as seen in the following statement:

> *"… If you are negative from the inside, then you will feel more and more pain to me. Because if you are negative, it makes you sick from the inside, it really just makes you sick from the inside…* (translated)

Maintaining a positive attitude and avoiding negative thoughts served as a coping strategy for these women, protecting them from negative experiences during the course of their treatment. But these were not the only personal coping strategies implemented by the women in this study.

4.5.1.2 Self-reported coping strategies. Several personal coping strategies emerged during the interviews but there were two of significance apart from a general positive attitude as described above. These included religious beliefs and prayer, and confidence in oneself. Those women who were religious reported that prayer and faith motivated them to persist through treatment and encouraged them to remain positive. Nobomi reported that prayer carried her through her journey when asked what she did to cope during treatment:

> *"Nothing much except praying. Prayer kept me...on top of things. Yeah...It soothed my soul. Um, I just hang on to each and every challenge or whatever I went through all because of prayer. Other than that, there is nothing special that I did on my own."*

Belief in themselves motivated women throughout their journeys with cervical cancer. This intrinsic motivation proved to be effective for those who believed they were in control and took ownership of their own well-being. Also, having persisted through previous hardships in life, such as losing loved ones or a partner due to illness, proved to foster a belief in participants' ability to overcome challenges. Tasha also acknowledge that getting through previous trauma in the form of her husband succumbing to a heart attack at a young age, leaving her to raise two young children alone, gave her experience in managing her outlook in relation to her disease. When asked how she remained motivated to continue through treatment she had the following to say:

> *"...to me basically it was me trying to motivate myself that I can do this. I've been through it. So, I... I think that for yourself you need to have like, a positive mindset in order to just like overcome things." (Tasha)*

Despite focusing on maintaining positive attitudes and outlooks throughout treatment, there were times where women reported that it was challenging to not succumb to negativity and pessimism.

4.5.2 Negative perceptions. Negative attitudes and beliefs were reported by several women in the interviews. Fatalistic ideas were present at diagnosis, but also during the duration of treatment for many women. Participants associated cancer with death, resulting in pessimistic cognitions and doubt in the treatment process.

4.5.2.1 Pessimism. Certain women who had experienced previous traumas and hardships initially related to the conceptualisation of 'why me?'. They demonstrated disbelief at their diagnosis, and their previous experiences seemed to confound the trauma of undergoing treatment, as evidenced by Michelle, who had previously struggled with depression and anxiety, stating the following:

> *"…it's like this can't happen to me you know, I've been through, you know cause I've had a, quite a hectic life so, I thought one more thing, I can't deal with this, it's just it's, it's gonna push me over the edge, hmm, and then you know the days just go on and you just deal with it day by day by day."*

Michelle shared feelings of denial and fear, and acknowledged a pessimistic attitude during treatment, constantly questioning whether it would be effective in healing her cancer and whether she was strong enough to endure. Treatment was, for the most part, described as traumatic, requiring strength and resilience from women throughout its duration. Certain women, such as Nina, reported feeling that they were not strong or motivated enough to complete treatment, resigning themselves to the possibility (or inevitability as was reported) of death:

"It was two weeks before I, I just felt like I didn't want to anymore, I didn't, I was just going to leave and I was going to drop the whole story, and if I was, if that's the end of me now so be it." (translated)

Questioning the efficacy of treatment, both during and after its completion, was reported by several women. These women held ideas that cancer could never truly be cured and questioned the purpose of undergoing treatment as they would always fear and anticipate its recurrence. Having such an outlook may negatively influence outlooks for the future and serve as a source of discouragement.

4.5.2.2 Fatalistic ideas. All fifteen participants in this study reported that their initial reaction to receiving a diagnosis of cervical cancer was negative; they were convinced that death was inevitable. For some women, this fear was replaced by optimism and proactive endeavours to improve their well-being such as seeking social support, gaining information related to treatment and self-care, and consciously challenging their negative conceptualisations as described above. Unfortunately, for others, this fatalistic attitude persisted. Maria describes her fear that she wouldn't survive cancer as follows:

"The hardest was hhh, one fact is, I just thought I was dying ... I thought, with me, with me it's just how it is, the name cancer ... Everyday day, really, there was every day in the beginning, that I said to myself, oh, I'm not going to live any longer." (translated)

Repeated negative cognitions throughout treatment persisted until the time of interviewing for certain women. Even following treatment, patients may doubt the efficacy of treatment and predict the return or persistence of cervical cancer. Such thoughts are spurred on by a lack of knowledge or understanding of cancer in itself and it's effect on the body. Ultimately, certain participants reported that they felt that cancer was a death sentence, despite the potential of curative treatment being effective.

"... I'm done, it's over, it's not long now, then I'm not going to be here anymore. That's just what I thought. I still think so every day. After all, cancer is not a thing that, after all, it's a heavy thing to carry..." (Karen) (translated)

Questioning how long they still had to live and constantly anticipating that cancer would ultimately lead to death weighed heavily on the women. This was clear in how emotional and reflective women became during the interviews when asked about these fatalistic cognitions which they described, especially for those who indicated that negative cognitions persisted until after treatment. These projections persisted for several of the women, evidenced by their current cognitions relating to their health and the outlook for their future.

4.5.3 Present thoughts and outlook for the future. Women in this study demonstrated both positive and negative cognitions and emotional reactions at the time of interviewing, while reflecting on their experiences, and when considering their futures. Two main subthemes emerged in relation to how women felt at the time of being interviewed after completing treatment; participants questioned whether treatment had been effective, but reflected positively on others who had endured the same treatment.

4.5.3.1 Fear that treatment was unsuccessful. For those participants who were yet to attend scheduled follow-up appointments succeeding the completion of treatment at the time of being interviewed, fear surrounding the efficacy of treatment was evident. Those women with a diagnosis of more advanced stages of cervical cancer (stage 3), questioned whether treatment could possibly be effective. Emotional turmoil was evident, and women appeared to be plagued by doubt and concern. It was also evident that a lack of understanding from those close to them, who chose to be optimistic for their loved one's treatment outcome, contributed to participants feeling isolated and not supported in the way that they wished to be. Karen was one such woman who felt that those surrounding her did not understand her

fear. She was still experiencing fatalistic cognitions and anxiety despite completing treatment:

> *"So they don't really know how it feels for you, like now, they don't know how it feels for me, that I now know, is it gone, is it still there, is it something to worry about, do I not need to worry about it, how long do I have to live, how long, there are a lot of things… "* (translated)

Certain women feared the recurrence of cancer in any form after another five- or ten-year's time, restricting their hopes for the future. This uncertainty and fatalistic attitude resulted in more fear for these women, despite treatment being completed and symptoms being alleviated.

4.5.3.2 Reflecting on the experience of treatment for cervical cancer. In opposition to the above-mentioned concerns, other women demonstrated a positive outlook for their future. Believing that treatment was successful and that they would not have any relapse or recurrence of symptoms. They acknowledged how difficult their experience was, but also emphasised their own strength and resilience which supported their perseverance indicating pride in themselves. When I questioned women about how they viewed themselves upon completion of treatment, participants were reluctant to speak too highly of themselves. What contributed to interesting insights was when I enquired about how they viewed women who travelled the same road as themselves. Women who had undergone treatment for cervical cancer were viewed by those who shared their experiences as strong, resilient, persevering and determined to overcome any challenge they encountered. Nobomi provided a beautiful description of the women going through cervical cancer treatment when asked how she viewed those who shared her experience:

> *"Gosh... They are rocks. They were not moved by this disease. They fought tooth and nail to see their families prosper, because most of the women are mothers. They have*

children that they would love to see prosper in life, and they hang in there just so they can see their families develop. To be there for their families, so they showed a lot of courage to have gone through this journey as well as to complete it."

Participants reported varying interpretations and approaches to coping when reflecting on their treatment journey for cervical cancer, both positive and negative. Maintaining a positive attitude and adopting coping strategies such as prayer proved to be of benefit to some, fostering a positive outlook for the future. Other women revealed that they had persistent pessimistic cognitions about the efficacy of treatment and feared that their cancer would recur. Despite varying attitudes, all of the women viewed those who had endured treatment in a positive light acknowledging their strength and resilience. Apart from personal attitudes, participants interactions with those deemed significant in their lives also influenced their experience of cervical cancer.

4.6 Influential Interpersonal Relationships

When exploring women's tendency to discuss their experiences with others and ability to accept support in its instrumental, informational and emotional forms, relationships with family as well as other women undergoing treatment for cervical cancer emerged as most important. Interestingly, the supportive nature of these relationships was not the most prevalent point of discussion. Rather, the nature of the interactions with these individuals and the role that they played in participants' lives appeared to be focal points.

Women had a tendency to prioritise their family members and loved ones ahead of themselves. This is abundantly clear in what the women in this study reported; especially so concerning those who were married or had an intimate partner, and those who had children. The women in this study revealed a tendency to want to protect their families from what they were going through; to rather project some type of normalcy. They did not want to attract attention or sympathy from their loved ones, and did not want to be perceived as a patient.

But concealing their feelings was not always possible as it meant distancing themselves from vital sources of support during difficult times. Interacting with other women undergoing treatment for cervical cancer served as an important source of support during this time as women were less concerned about the burden they placed on these women and could benefit from unaffected support and encouragement. Therefore, three main subthemes emerged when I explored interpersonal relationships; the role of partner involvement, child involvement, and women encountered in the waiting room who shared a common experience.

4.6.1 Partner involvement. Several women reported that symptoms of the disease caused issues in their relationships due to sexual limitations such as pain and bleeding during intercourse, and ultimately this led them to seek medical attention. Concern for their relationship was more important to them than their concern for themselves. They put their partners and their relationships ahead of their health and well-being. Nobomi illustrated this phenomenon by stating the following:

> *"…And at the time, more than my health, I think that the one fear that I had is that this is ruining my relationship! That was the only fear that I had! More than medical or health fear..."*

Partners either played a supportive role in the women undergoing treatment's lives, or worsened their experiences by adding stress due to threatened emotional security. In this study, seven women reported being in a relationship while four reported being married. Their descriptions of the roles that their partners played in supporting them during their experience of cervical cancer ranged from positive to negative. Several subthemes emerged in relation to partner involvement, namely; partner reactions, the importance of supportive and proactive partners, and fear of losing a partner as a result of the disease.

4.6.1.1 Partner reactions. The women in this study did not hesitate to share their diagnosis with their partners; in fact, their partners were often the first individual that they

disclosed this information to. They mostly reported an optimistic and supportive reaction from their partners despite partners demonstrating shock, disbelief and even denial. The one emotion that the women echoed in terms of their husband's reactions to their diagnosis was fear. Despite partners demonstrating fear and uncertainty, most of the women in the study reported that their partners stood by them, encouraged them and were proactive in learning more about the condition. This was in contrast to what the interviewees expected of their partners. Women were fearful that their partners would see them as damaged and anticipated being abandoned during their journey with cervical cancer, yet these fears were not realised for the most part. There was only participant, Nobomi, that reported a negative experience with her partner. Nobomi initially experienced her partner and father of her child as supportive in response to her diagnosis, but this changed over time:

> *"On the day that I found out he was very supportive. But throughout the journey of treatment and all of that he started to pull away…He was great in the beginning, then during the treatment I could say it was non-existent... Like, he was just not there. He was just not there."*

He ultimately terminated their relationship, but fortunately Nobomi had a friend (now her partner) who stepped into the supportive role. She described him as proactive in learning about the disease; providing insights that he had learned which could help her. Most importantly, after being negatively received by her previous partner, Nobomi reported that she felt that her new partner was "also not judging [her] for having the disease", which led her to feel loved, supported and accepted.

4.6.1.2 The importance of supportive and proactive partners. Participants reported that proactive and supportive partners buffered against the negative experiences associated with undergoing treatment for cervical cancer. Instrumental support such as being financially supportive and caring for children, but also in being emotionally supportive. Assistance with

childcare, particularly in supporting children emotionally while their mothers were unwell or absent due to treatment, may take pressure of mothers. Partners providing financial aid or stability, and accompanying participants to treatment, was an important source of support to participants. Several women reported that their husbands drove them to the hospital, and continue to attend follow-up consultations alongside them. Karen, who had two adult children with her husband of 26 years, echoed these sentiments highlighting how grateful she was to have her husband with her:

> *"I didn't go through it alone, I went, my husband went with me to Worcester, he went with me to Hermanus, he sat there the whole time."* (translated)

The women appeared to be grateful for the instrumental support and assistance that they received but also valued their partners being compassionate, understanding, attentive and patient with them during their experience. In these relationships, women felt a sense of worth in response to their partners' behaviour, and in turn it appeared as though a focus shift occurred. Validation of traumatic experiences and emotional support for women undergoing treatment for cervical cancer may strengthen the relationship between partners. Jean indicated that the whole experience brought her and her husband closer together, and even their whole family unit. Having a supportive partner during that difficult time of her life led to her prioritising her husband and his well-being, changing her perception from 'I' to 'we'.

> *"…because it's not just about me right now, it's about him too, because it's a whole life changing experience for both of us… so he also has to talk if something is wrong, if he feels pressure, then he has to talk…"* (translated)

Women who reported feeling valued and supported demonstrated less fear and insecurity in their relationships than those who felt that their experiences were dismissed by their partners. These sentiments were not echoed by those who did not have the same level of support.

4.6.1.3 Fear of losing partner as a result of the disease. The women who were in relationships revealed concern with regards to their partners remaining with them throughout the treatment process which was to follow. Three main factors seemed to influence this reaction: the perception that they were diseased, hindrances to their intimate lives, and an inability to conceive and carry a child. Tasha, who was in a relatively new relationship at the time of her diagnosis, captured the fear of being perceived as diseased and a burden:

> *"When they told me, I came home and then I just said okay. These are my things. I don't want you to stay with me because I'm diseased now…"*

During treatment, and for months afterwards, women reported that they were either unable to be intimate with their partners, or had no desire to consent. The physical symptoms of the disease as well as the side effects of treatment often left women feeling unwell, which reportedly created a physical distance between them and their partners. They feared that this would push their partners away. Fortunately, these fears were not realised as their partners were reported to be supportive and understanding. Confidence in a relationship, mostly due to reassurance and understanding from a partner, may foster feelings of security in the relationship which allows the woman to prioritise herself and her health despite a negative impact on intimacy.

> *"… between me and my husband things still, I took a long time before I slept with him again, I did, really, it was probably something like, 6 months… because I was scared, but a doctor told me I didn't need to be scared, so… But yeah, it was just, it was a, I was very scared and my husband understood… he understood so. It wasn't an issue for us now, which could have come between us."* (Jean) (translated)

It was communicated to the participants before treatment commenced that it was unlikely that they would be able to conceive a child due to the treatment they were to receive. This was a source of great concern for many of the women who had partners as their worth as

a partner was internally tied to their ability to give their partner a child as part of their traditionally conceived roles of being a woman. Being unable to uphold the expectations held of a woman and partner compromised the participants' view of themselves and their worth. Only those who were particularly secure in their relationships, with very supportive partners, were able to overcome these negative cognitions. Tasha captured this concern when asked whether she felt at ease and secure with her partner; despite his reassurance, her fear persists:

> *"…no, I never felt secure the whole time. Like, even now. I'm like still like I can't give you kids, you know, obviously as females you would obviously… you want that. So, and I know I can't give you the kids like, why are you here? You don't have any kids. Maybe If you find someone else that can give you kids, you'll be much happier. Well, I don't know because I won't be able to fulfil that part of your life for you, you know. And I want you to experience it... But he keeps on reassuring me that it's okay."*

4.6.2 Child involvement. When enquiring about what women's first thoughts were upon receiving the news that they had cervical cancer, all of the mothers first thoughts related to concern for their children. Participants communicated that they felt being unable to engage in normal daily activities with their children had a negative influence on both their own and their children's well-being. However, for some women, having an older child was reported to be a source of support and also a source of motivation to adhere to treatment.

4.6.2.1 Children as a source of motivation to persevere. The women in this study revealed that persevering and fighting the disease was something that they did for their children, as it was what was expected of them as mothers. They demonstrated a drive to persevere through treatment and to take care of themselves in order to support their children, ensure their safety and witness their lives. Even during the difficult times, women reported that their children served as their motivation to survive:

> *"There were days...there were days but even with those days I kept telling myself " I cannot give up". I have a son to raise. I need to watch him become the pilot he wants to become. And it's not my time. I am fighting this, and I am going to be victorious. I just kept telling myself all of that each and every day." (Nobomi)*

Being a mother encouraged many positive elements during treatment, and following it, as a result of the sense of responsibility that the mothers felt towards their children. Even when they had to be the support system that they needed to be a recipient of, the role of being a mother superseded the need for support. For one participant in particular, Felicia who gave birth just before commencing with treatment, having a child was a particular source of motivation and drive to get healthy, despite her understandable fear and reservations throughout her diagnosis and treatment process. Thankfully, she received much other encouragement and support from her family, through her faith and from those helping to care for her children:

> *"…then she said to me, if the Lord wanted to take me away so much, then he would not have given me a baby again… and it gave me courage."* (Felicia, 32-year-old mother of four) (translated)

4.6.2.2 Children as a source of support. For those women who had older children, able to understand what cervical cancer was and what their mother was going through, their children served as a source of support and encouragement. Several participants reported that their children, specifically older daughters served as a source of information during their journeys as they were educated on cervical cancer and HPV at school. Children therefore served as a source of informational support. This was the case with Anna (mother to a 17-year-old daughter) who reported the following:

"... then she could also tell me but they say that it about it, they say this about cancer, cancer does this… then I thought ok no, you are actually a little bit clued up, because you have done it now…" (translated)

Even during the times where women reported feeling that they had no hope left, when they were discouraged during treatment and unsure of the future, their children would uplift them. Women reported that their children were understanding and respected their privacy and needs during this time. They could recognise the needs of their mothers, which may have taken pressure off of participants and allowed them to focus on themselves. Karen described how her adult daughter almost took over the parenting role in the house, directing her mother to take care of herself.

"She's the strong one. She also tells me, if you're in pain, go lie down, that's where you belong, you know it. Why are you still walking around here?" (translated)

Not all of the women in this study had partners to support them at home, or children to concern themselves with, but all encountered other women that were going through similar experiences in their journey with cervical cancer at the clinic where they were receiving treatment.

4.6.3 Women in the waiting room. Interacting with other women who were undergoing treatment for cervical cancer proved to be a significant source of support for most of the women in this study. These interactions started in the clinic waiting rooms where women began to recognise familiar faces and eventually initiated or succumbed to conversations with others wanting to share. These women proved to be a source of information and encouragement, and the participants in this study reported that a sense of understanding and belonging contributed to a feeling of community among these women. A feeling of being 'in it together' was echoed by several of the women as they were walking the same path and sharing experiences. Sonja, a widowed mother of two who was diagnosed with

stage III cervical cancer provided the following explanation regarding why women were bonding with one another while waiting to receive treatment:

> *"... now it's that time you got a certain bond with them that's it ... one thing I have to say because, ai you are all on the same level ... I just call it the same level because you are doing exactly the same things, same doctors, same machines… you just do everything yourself and you wait for the same time…"* (translated)

The women reported that at first, they felt alone and afraid of what was to come in terms of treatment, but encountering other women who shared their experiences and were receptive to forming a relationship with them was beneficial. Friendships developed and as a consequence a sense of support. Apart from being receptive to support from others, these interactions with women undergoing treatment for cervical cancer also allowed participants to act as a source of support and encouragement. Women reported that they felt more equipped to be supportive to other women. This may be due to first-hand experience of such support from other women and how valuable it can be in terms of being understood. The following account from Maria illustrates how she was able to support another woman who was just starting with her journey:

> *"… Because at that time we, we were a lot of young people, then I see oooh, she's actually very down, then I move closer and then, then I talk and then I tell her, in the beginning when I was here I also felt like that, but then I just say, just be positive, then I say I'm praying for you, I'm going to pray for you, you're going to come through this."* (translated)

For several of the women the support extended beyond the waiting room as they endeavoured to continue communicating with others. They created a support network through which they communicated telephonically or via WhatsApp Messenger to check in and encourage one another. These women had access to both informational and emotional

support. Relevant and information deemed to be accurate was readily available from trusted sources and shared amongst the women pertaining to treatment effects to be expected and how to manage them. Also, women felt understood and an empathetic environment was created where women communicated with one another and provided emotional encouragement and inspiration by checking in. Most importantly, women felt understood due to their shared experience, and validated as they felt that they had something to contribute in terms of support due to their experiences. For those who partook in such interactions, it proved to be a major source of comfort, which influenced their attitudes and outlooks throughout the trajectory of their cervical cancer experience.

The interpersonal relationships that women undergoing treatment for cervical cancer place value on may mitigate against the negative impact of their journeys. Partners, children and other women undergoing treatment for cervical cancer play an important role in supporting these women and serve as a source of motivation to persist through treatment and to strive for well-being during this experience.

4.7 Conclusion

The focus of this research was to explore women's psychosocial experiences over the trajectory of cervical cancer. In order to realise this goal, I aimed to explore how women conceptualized cervical cancer according to their prior knowledge and attitude towards the disease in general. I also sought to explore participants' experiences relating specifically to; diagnosis and treatment, perceived support and sources thereof, and factors which may influence their well-being. Fifteen women who received treatment at Tygerberg Hospital, Cape Town were recruited to participate.

Initially, women's experiences were organized according to disease, diagnosis and treatment factors. From the data it emerged that women sought professional healthcare in response to the symptoms they were experiencing such as fatigue, abnormal bleeding and

pain. For some, there was concern from the onset that cervical cancer could be the cause of their symptoms, spurring them on to obtain a Pap smear. For others the process was more arduous as the journey to diagnosis was paved with misdiagnoses and poor guidance from both friends/ family and healthcare professionals. Reactions to such a diagnosis varied greatly with emotions such as denial, shock, confusion and fear dominating; the idea that cancer is associated with death was held by all participants involved. Once treatment commenced, healthcare providers played an important role in mediating against fear and uncertainty as they served as sources of information and emotional support. Communication therefore played a vital role.

The knowledge relating to cervical cancer at the onset of the participants' journeys was related to communication, which allows for the dissemination of information both to and from participants. Therefore, knowledge and awareness played a vital role in participants' confidence in sharing their experiences with others. Prior knowledge relating to cervical cancer and Pap smears was limited among the participants, which I expected as prior studies indicate as much. Unfortunately, women reported several incidences where misinformation pertaining to the cause and treatment of cervical cancer were prevalent, influencing both how participants viewed themselves and how others viewed them.

Stigmatic ideas relating to promiscuity causing cervical cancer and the misconceived notion of it being contagious proved to weigh heavily on most women. Interestingly, stigma was rarely identified by women in the interview, yet the consequences of stigma were evident. Feelings of shame and embarrassment resulted in women withdrawing from others who were possible support systems, and resulted in resistance to disclose such a diagnosis. The extent of a desire for privacy varied greatly among the women, and the choice of whether or not to discuss their diagnosis and experience of treatment related more to who they intended to share it with.

Personal characteristics, available information and sources of support, combined with the stigmatic notions surrounding cervical cancer, influenced the outlook that women held in relation to their futures. For some, a pessimistic attitude and fatalistic ideas fostered fear that their cancer was not, and could not be, cured. However, a positive attitude, coping strategies and appropriate sources of support emanating from interpersonal relationships helped to foster hope. Partners and children proved to be the most important confidants, as well as the women who were sharing the common journey of cervical cancer treatment. Participants placed importance on these relationships, and the quality of these interactions influenced women's experiences of curative treatment for cervical cancer. More confidence was evident in those participants who had secure relationships with their partners, who had children that could serve as a source of support during such difficult times, and who chose to interact with women in the waiting room.

Chapter 5
Discussion of Findings

5.1 Introduction to Discussion Chapter

In this chapter, I aim to conceptualise the main findings of the study in the context of the illness intrusiveness theoretical framework. I then discuss the main themes that emerged in the study by situating the themes in the available literature.

5.2 Conceptualising the Themes Using the Illness Intrusiveness Theoretical Framework

As described in chapter 2, the illness intrusiveness theoretical framework conceptualises the role of illness intrusiveness, disease and treatment experiences on subjective well-being (Devins et al., 2001; Devins et al., 2006). The model helps us take into account the role that psychological, social and contextual factors play in the experiences of women who have undergone treatment for cervical cancer. The interview schedule for this study was based on this model and the findings demonstrate the model's applicability to women's individual experiences of cervical cancer. In this section I will first situate the themes according to the categories of disease/treatment factors, illness intrusiveness and psychosocial influences and then critique the applicability of the model in the specific context of this study.

The illness intrusiveness framework accounts for contextual factors that may influence women's well-being during and following cervical cancer treatment. Both disease and treatment factors are implicated as influencing subjective well-being (Devins et al., 2006; Mah et al., 2011), and the diagnosis process can also be considered part of the initial experience of women who underwent treatment for cervical cancer. This accounts for the symptoms that women endured prior to being diagnosed with cervical cancer, as well as the physical effects of treatment resulting from chemotherapy and/or radiation, and their reported influence on participants' well-being. As the model stipulates, such experiences influence subjective well-being via illness-intrusiveness (Devins et al., 2006; Devins, 2010).

Several new themes from this study can be incorporated into illness intrusiveness to explain their influence on women's well-being. As previously mentioned, illness intrusiveness incorporates three domains, namely; relationships and personal development, intimacy, and instrumental domains (Devins et al., 2006; Mah et al., 2011). The findings of this study relating to how women reacted to their diagnosis of cervical cancer, whether they chose to share their diagnosis with others, the knowledge and understanding of the disease which they reported, as well as their outlook for the future can be considered in the context of personal development. Women's relationships with their children and partners, as well as the dynamics that arose within these relationships as a result of their treatment, formed a vital part of this initial domain. Finally, disruptions to women's daily lives as a result of either the disease itself or the treatment thereof can be considered within the context of instrumental domains (Devins et al., 2006), which are influenced as a result of these women's experiences.

Psychosocial factors played an important interceding role, as it does in the model, as they influence both the experience of disease and treatment factors on the individual level, but also the influence of illness intrusiveness on well-being. The role of communication, which arose from women's experiences during cervical cancer treatment, played a particularly important role here, along with their interactions with healthcare providers and other women who underwent treatment for cervical cancer. This is due to the supportive nature of these interactions; women felt emotionally and informationally supported which influenced their knowledge relating to their disease, how they conceptualised it, and eventually the decisions they made in terms of sharing their experiences with others. The stigmatising ideas that women were exposed to demonstrated a similar influence on illness intrusiveness domains and how women interpreted their experiences during treatment. Finally, in terms of psychological factors, a positive attitude or pessimistic perception of the

disease and its possible outcome also influenced the intrusiveness of the disease and ultimately the well-being of these women.

The illness intrusiveness theoretical framework postulates that the influence of contextual factors, and the effect of both disease and treatment experiences, on daily life and activity can be understood (Devins, 1994). This is particularly relevant in this study in relation to the younger age of participants (with a mean age of approximately 38), as most participants in other studies were generally older. The average age of participants in Du toit and Kidd (2013) was 49 years, in Ntinga and Maree (2015) was approximately 44 years, and in Sabulei and Maree (2019) was approximately 50 years, to name but a few. This may have resulted in different experiences of intrusiveness during participants' illness in comparison with other studies. An example of this is that many of the women in this study were still concerned with fertility preservation and had young children that they were responsible for, whereas in another study women reported more concerns with financial implications and changes to body image in response to treatment (Ntinga & Maree, 2015).

Participants tended to report distress and fatalistic ideas in response to their experiences, perhaps due to the fear they reported for their children. Devins et al. (2006) echoed this finding; illness intrusiveness was demonstrated to be worse in younger patients with cancer than older individuals. They expanded on this finding by suggesting that young people struggled to come to grips with the concept of having a disease associated with old age, which threatened their physical vitality (Devins et al., 2006). An explanation for this phenomenon was that individuals faced different developmental challenges in accordance to their age (Devins, 2010).

The illness intrusiveness theoretical framework facilitates a general understanding of how various factors influence subjective well-being in women who undergo treatment for cancer, yet limitations exist in utilising this framework in the context of this study. The

complexity of the interaction of the different psychosocial and contextual factors on illness intrusiveness is not grasped by the model, and certain variables are not explicitly accounted for. South Africa is culturally diverse, yet the role of culture in the illness intrusiveness theoretical model is not clear. Devins (2010) indicated that it would be important to further determine cultural equivalence and influence in terms of quality of life and well-being of individuals. Mosavel et al. (2009) support the notion that culture affects the way that we interpret an illness. Cultural beliefs may influence the importance that women place on certain psychosocial factors such as gender roles, social support and communication, therefore moderating their experience of cervical cancer treatment and subjective well-being interpretation. Cultural influences were evident in several areas in this study; traditional gender roles were expressed by several women relating to the ability to conceive a child, and women's resistance to disclose their diagnosis may relate to fear of being exposed to stigmatising ideas within the community.

Another limitation that I found in interpreting the findings of this study using the lens of illness intrusiveness is that certain variables and influences played roles which were not accounted for in the structure of this model. The interplay of certain factors is more complicated than what can be interpreted in this model in that factors such as stigma and communication may both play a psychosocial role, but they also influence one another. For example, the fear of being stigmatised due to having a disease such as cervical cancer was reported to influence women's willingness to disclose their diagnosis to individuals outside of their immediate family. Furthermore, resistance to disseminate information about the disease, information which may be more accurate than what is commonly perceived within the community, fed stigmatising ideas. Also, certain characteristics of the women in this study, namely their attitude during treatment, could be categorised as either part of the domains of illness intrusiveness or as a psychological factor. Despite this, with more flexibility in

interpreting the results of the study I was still able to glean a valuable general understanding of the manner in which women's experiences influence their well-being during and after treatment for cervical cancer.

5.3 Disease, Diagnosis and Treatment Factors

Women reported varying degrees of severity of cervical cancer symptoms relating to fatigue, abdominal pain and vaginal bleeding (likened to that associated with menstruation), and pain and bleeding accompanying sexual intercourse. For many women, the fatigue which they experienced prior to a diagnosis was the most prominent symptom in terms of its effect on their daily lives, which echoes the findings of both Ntinga and Maree (2016) and Sabulei and Maree (2019). Several studies have postulated that such adverse symptoms severely influence the well-being and quality of life of women with cervical cancer, in that it could lead to women isolating themselves socially due to fear of embarrassment (Sabulei & Maree, 2019), indicating the psychosocial impact of the disease. Ntinga and Maree (2016) elaborated on the significance of the role of pain and fatigue by adding that these symptoms inhibit women from engaging in daily activities, as seen in this study. Not being able to partake in life fully ultimately contributed to the distress that women described. Women reportedly recognised that their symptoms were abnormal when their daily lives and relationships were negatively affected. Unfortunately, for many women, the adverse symptoms that they were experiencing were not initially sufficient to motivate them to seek professional care.

Several women reported that their first interpretation of the fatigue, pain, heavy vaginal bleeding and bleeding following intercourse was misattributed to other causes. Participants assumed that their symptoms were associated with abnormalities in their menstrual cycles, menopause (for those at an appropriate age) or pregnancy complications. This misinterpretation of the symptoms may be attributed to the lack of knowledge surrounding cervical cancer which is reported by several studies (De Abreu et al., 2013;

Maree & Wright, 2010). Ultimately, by not recognising their symptoms, the diagnosis process was delayed and late presentation with symptoms was evident, corroborating the findings of Maree et al. (2014).

Pap smears were the main indication of abnormal cells among the women of this study, which set them on their diagnostic trajectory. Although women acknowledged hearing of Pap smears before, they considered them to be for the purpose of diagnosis in response to adverse symptoms, confirming the findings of Momberg et al. (2017). Women were more likely to consider a Pap smear to be a diagnostic tool over a preventative opportunity (Momberg et al., 2017), with the motivation to find relief from the symptoms they were experiencing (De Abreu et al., 2013). Three women reported that they received negative results from Pap smears during to their initial health seeking initiatives at local clinics. This corresponds with a statement made by Ntinga and Maree (2015) where they suggested that women who seek care for cervical cancer were repeatedly 'let down' by the healthcare system, which inhibited the possibility of an early diagnosis being made and facilitated late presentation with symptoms and a diagnosis of more advanced cervical cancer.

Shock was the foremost reaction of all of the women in this study upon hearing that they had cervical cancer; later shifting to feelings of denial and distress. This corresponds with the outcomes of Jansen van Rensburg et al.'s (2017) study which found that women were fearful of the positive diagnosis which they received, apprehensive of the treatment to come and feared dying. Another element that arose, one echoed by Ntinga and Maree (2015), was that women questioned why they had cancer, which either indicated that they were uncertain as to what could have caused the disease or ultimately would blame themselves which may be where feelings of shame started to develop. In spite of the road to a diagnosis being complicated at times, and the reaction to their diagnosis varying, women generally had

positive encounters with healthcare practitioners from that point forward despite the trauma of hearing that they had cervical cancer.

Healthcare providers occupied a significant position influencing women's experiences from the point of diagnosis. Most of the women in this study reported that the information that they received from their healthcare providers laid to rest some of the uncertainty and anxiety they held in anticipation of treatment. Therefore, communication from healthcare providers had the potential to improve women's well-being during their treatment trajectory, which may have extended beyond that period. In contrast to my findings, Ntinga and Maree (2015) reported that women felt that they did not receive adequate information from the healthcare workers they encountered about what to expect in terms of treatment and the disease itself, which negatively affected their quality of life. From the above it is clear that the quality of communication between patients and doctors/nurses influenced women's perceptions of their cervical cancer journey and what to expect of treatment.

The side effects that women experienced in response to their treatments were unique in combination, but pain and fatigue as well as modifications to sexual functioning were reported by most women. Exhaustion and fatigue also specifically had a negative impact on women's ability to work. Ntinga and Maree (2015) indicate that a loss of capacity to work had a significant influence on women's ability to provide for themselves and their families, resulting in socioeconomic consequences which had a negative effect on their standard of living. Both Sabulei and Maree (2019) and Ntinga and Maree (2015) corroborate these findings, suggesting that these symptoms majorly influenced women's well-being and quality of life. Specifically, changes to sexual functioning may influence body image, and along with other adverse symptoms, combine to influence women's physical, psychosocial, emotional and sexual well-being (Ntinga & Maree, 2015). Women's normal daily lives were dramatically disrupted.

5.4 Knowledge, Communication and Stigma Related to Cervical Cancer

Several subthemes emerged relating to the knowledge and understanding that women possessed regarding cervical cancer, how they communicated this information to others, as well as the stigma that influenced both their knowledge of cervical cancer and their disclosure to others.

5.4.1 Knowledge and understanding of women relating to cervical cancer.

Participants reported limited or no knowledge specifically pertaining to cervical cancer. Women reported that they knew of cancer in general, often due to family members having had such a disease, but the knowledge was shrouded in fear, ignorance, misunderstandings of a prognosis and treatment, and stigmatic ideas. A lack of knowledge relating to cervical cancer was reported in several South African studies (De Abreu et al., 2013; Hogue & Hogue, 2009; Maree & Wright, 2010; Mosavel et al., 2009) and this lack or limited knowledge acted as barriers to health seeking behaviour among disadvantaged women (De Abreu., 2013). In the current study, this limited knowledge also resulted in reported delayed seeking of care by many women. Interestingly, limited knowledge was apparent regardless of demographic characteristics relating to income, race or education level among the women. Mosavel et al.'s (2014) study revealed similar findings; poor insight into cervical cancer and its risk were evident in even well-educated women.

Those who reported having prior knowledge of cervical cancer indicated that it was by chance as they had at some point been exposed to information at clinics or via media sources such as magazines. This indicates that information drives relating to cervical cancer were successful to a degree. This may contradict the findings of Maree and Wright (2010), who reported lack of knowledge of cervical cancer among participants despite awareness campaigns and efforts at increasing cervical cancer screening in South Africa. However, that

study was conducted 10 years ago and perhaps the current findings indicate that exposure to information relating to cervical cancer has a greater reach today than previously.

Most women in this study assumed that cervical cancer was hereditary, and those who had family members who had had cancer revealed a perception of the inevitability of developing such a disease. Patients also stated that tobacco smoking and sexual activity were causes for the disease. Both smoking and multiple sexual partners are listed by Stewart et al. (2018) as contributors to the development of cervical cancer, but they also suggested that they were confounding factors rather than singular sources of causation. Despite suggesting a sexual origin, women did not communicate knowledge of HPV or any viral causes of cervical cancer, but these factors have been widely reported causes of cervical cancer (Cooper et al., 2007; Laubscher et al., 2015; Pillay, 2002). This underscores the limited knowledge about cervical cancer and cervical cancer prevention.

Women acknowledged that they heard of Pap smears prior to their diagnosis, but voiced little insight about the intended purpose of the procedure. Most women reported that they had never undergone a Pap smear, indicating that they had never felt a need to as there were no symptoms that warranted such a procedure. Both De Abreu et al. (2013) and Maree et al. (2014) suggested that undergoing Pap smears and seeking medical care only occurred at the onset of symptoms as women were seeking to alleviate the problem; it was either perceived to be a diagnostic tool or just something that they had to do as woman.

Motivation to learn about and overcome the disease was evident among the women in this study, indicated by their drive to improve their lifestyles and desire to protect their children. Gaining knowledge and understanding related to cervical cancer provided the means to do so. Gaining accurate information about cervical cancer and its causes also enabled women to better equip their children with knowledge of how to prevent contracting HPV and therefore cervical cancer. According to Leser and Francis (2014), women in their study felt

that they had inadequate information regarding sexual health issues to convey to their children in order to promote their understanding of the disease, yet the women in this study for the most part indicated that they felt equipped to do so.

5.4.2 Role of communication. Participants claimed that cervical cancer was an avoided topic of conversation, and discussing their experiences with others was not the norm despite these women being equipped to convey accurate information.

Women commonly reported encountering misinformation, and such information was often propagated by individuals in women's communities and families who did not acquire accurate knowledge of the concepts being discussed. This relates to Maree et al.'s (2014) discussion which attributed the communication of misinformation to a lack of information to start with. Further to this, some women reported that questionable information was also communicated to them by the initial healthcare providers where they sought care in this study. Misleading and discouraging information about the prognosis of cervical cancer was readily conveyed prior to a diagnosis being confirmed or consultation with a specialist, which runs the risk of fostering fatalistic and negative perceptions of the disease (Mosavel et al., 2009; Mosavel et al., 2010). This indicated that the prejudices and stigmatising ideas of those healthcare workers who were initially encountered (mostly reported to be in the clinic setting) was projected onto patients, fostering fear and stifling the will of women to communicate with others. Hogue and Hogue's (2009) survey with 389 South African students (females) revealed that approximately 42% of the sample who had heard of cervical cancer reported that their initial source of information was an individual from the medical field (either a community health worker or healthcare provider). It is therefore concerning that these prominent sources of knowledge may communicate inaccurate and discouraging information to patients.

Despite women's resistance to discuss their experiences, they acknowledged that the propagation of knowledge was necessary to counter the misleading information and stigmatising ideas prevalent within their communities related to cervical cancer. Being able to effectively communicate information to their children was also regularly reported. Both Leser and Francis (2014) and Mosavel et al. (2010) acknowledged that parent communication served an important role in the dissemination of information to daughters, which resulted in improved awareness and behaviour in relation to health beliefs and sexual behaviour. Therefore, effective communication between the women of this study and their children should serve as a protective factor against contracting HPV. It may therefore be important to empower these women with information and insight into cervical cancer for them to act as equipped agents for the effective propagation of knowledge which would serve to counter the misconceptions which exist regarding the disease.

5.4.3 Stigma. Stigmatising ideas were never explicitly described by the women of this study, yet could be identified in their reported thoughts and experiences. Stigma influenced the way these women conceptualised their diagnosis and prognosis of cervical cancer, and was apparent in how they described their reactions to their diagnosis, their attitudes towards and knowledge regarding the disease, and their willingness to share their experience with others. It is well established that negative stigma towards gynaecological cancers was prevalent in South Africa (De Abreu et al., 2013; Learmonth et al., 2015). Both community and cultural factors shaped the attitudes that individuals had towards a disease like cervical cancer and therefore influenced the stigmatising ideas associated with it (Maree et al., 2014; Mosavel et al., 2009; Mosavel et al., 2010). Stigma ultimately may have led to the women in this study to experiencing feelings of shame and confusion, leading to concealment of their condition and isolation which silenced open communication.

Several women reported that they encountered stigmatising ideas from others relating to cervical cancer being caused by promiscuity and multiple sexual partners. This finding echoes the results of several studies which explored the stigma experienced by women with cervical cancer (Chirwa et al., 2011; Learmonth et al., 2015). It was also reported that the blame was placed solely on the women in this study which was especially distressing for those who had only had one sexual partner. This links to the cultural influence on gender roles and bias which was discussed by Maree and Wright (2010); gender bias related to gynaecological cancer and the causation thereof places the responsibility on the shoulders of the woman.

5.5 Disclosure versus Nondisclosure of Diagnosis

The decision of whether or not to disclose a diagnosis of cervical cancer proved to weigh heavily on the women in this study. The decision was twofold; whether they should share that private information with another individual, and the choice of who to share it with. A desire for privacy versus a need to be transparent was reported, and women were situated at various locations along the continuum between these two extremes. Resistance may have been influenced by the stigmatising ideas held by community members **(**Learmonth et al., 2015; Maree et al., 2014). Other women were not as subject to the feelings of shame described by many participants and chose to be transparent and more open to sharing their diagnosis and journey with others.

Women reported that they feared the judgment of others in response to the information that they had cervical cancer. Fatalistic attitudes and projections along with discouragement from others were often witnessed in social networks, dissuading women from being open about their experiences. Leser and Francis (2014) explained this phenomenon; the manner in which women with cervical cancer have been accepted within their communities is influenced by the perception and attitudes of others towards the disease. If women felt that

they would experience judgment and stigma they may avoid disclosing information which would leave them exposed and vulnerable to the negative perceptions of others. Attitudes and beliefs regarding cervical cancer were often times culturally bound and evident within women's communities, but also shaped the way that women perceived themselves **(**Learmonth et al, 2015; Maree et al., 2014; Maree & Wright, 2010; Mosavel et al., 2009; Mosavel et al., 2010). Maree et al. (2014) further explained that this cultural influence on the perception of a disease ultimately influenced the decisions and health-seeking behaviour of women with cervical cancer. Individuals within the community may be influenced by stigmatising ideas which they then project onto women who had the disease. Therefore, in a community where stigma relating to gynaecological cancer is evident, women may be more resistant to disclose their diagnosis, choosing privacy over transparency.

A dilemma that arose for women was choosing those whose reactions they could predict and who they could trust with personal information. Women stated that being transparent with their partners was easy, which for the most part solidified an important source of support for women during stressful life events. Honesty and transparency with a partner were reported to make women feel loved and supported during their journey, reinforcing the findings of Carpenter et al. (2010). Carpenter et al. (2010) stressed that confiding in a loved one and having an established source of emotional support in a companion buffered against the emotional consequences of disease, thereby promoting well-being during women's stressful journeys with cervical cancer.

When it came to sharing a diagnosis of cervical cancer with children, especially young children, women unanimously indicated that they wanted to protect their children. The single mothers who had young children reported the most resistance to disclose information to their children for fear of being a burden on their children and fostering anxiety. The age of the child was therefore a determinant in deciding how much information to give the child.

Carpenter et al. (2010) accounts for that fear and anxiety which may be provoked in children in response to their mother's diagnosis by explaining that family members experienced poor psychological effects in reaction to a loved one's adverse experiences. It was important to consider what a child would be able to understand and conceptualise in terms of cervical cancer before disclosing an appropriate amount of information. This supports the statement made by Pillay (2002) with regards to considering the target audience when selecting the means of communication as information needs to be disseminated in a fitting manner in order for it to be understood and conceptualised optimally.

5.6 Psychological Experiences Throughout Cervical Cancer Treatment

The women in this study described various attitudes and intrinsic responses to both the diagnosis and treatment of cervical cancer, many of which persisted until the time of being interviewed following the completion of treatment. Two broad categories emerged from the data relating to either a positive or negative attitude in response to these women's experiences, which influenced their outlook for the future.

Several women demonstrated a positive attitude and reported on coping strategies which they employed to moderate the trauma of their experience during the trajectory of cervical cancer. Despite adverse challenges, these women were able to maintain a positive attitude and motivation to persevere in order to overcome both the physical and emotional hardships they faced. Treatment was positioned within a positive light and considered to facilitate healing. Maree et al. (2014) described how the perception of treatment can be shaped either positively or negatively by those with cervical cancer, which then influences patients' subjective well-being. They indicated that women who viewed treatment as a means to relieve the adverse symptoms of the disease, much like the women in this study, had a more positive outlook for the efficacy of their treatment than those who projected a more negative attitude. By focusing on the efficacy of treatment rather than the possible side-

effects or reoccurrence of cancer, these women were able to avoid the overwhelming weight associated with their disease which threatened to negatively influence their well-being.

Belief in oneself was commonly reported by women, indicating a focus on their own autonomy and what was within their power to control. These women took ownership of their health and took steps to manage the way that they viewed their experience with cervical cancer in order to maintain a positive attitude. Another commonly reported source of comfort during their experience was religious beliefs. Jansen van Rensburg et al. (2017) reported that cancer patients found hope, courage and peace in their religious beliefs and through prayer, which was confirmed in this study. This courage ultimately created a belief in self which allowed their participants to "get their lives in order" (Jansen van Rensburg et al., 2017, p.339), which contributed to improved well-being and belief in oneself which is also evident in what the women of this study reported. Women demonstrated a positive outlook for the future, a belief in their own resilience and pride in themselves. They also viewed other women who had shared their experience in the same positive light.

A minority of women participants reported negative outlooks and interpretations of their experiences. For these women, pessimistic ideas were persistent and presented in the fatalistic attitude's women revealed in relation to their experiences and future outlook. As mentioned by De Groot et al. (2005) the psychosocial consequences of cervical cancer may persist beyond the physical factors, meaning that the negative influence of the disease on women's attitudes and beliefs extends beyond treatment. The fatalistic conceptions may therefore have persisted despite the alleviation of the physical symptoms of the disease following treatment, which ultimately supressed subjective well-being. Evident among those with negative attitudes towards their experience was the dominating fear that treatment was not successful, which fuelled their fatalistic ideas and restricted their plans and hope for the future, and fostered anxiety.

Several women projected a poor outlook for the future, questioned the efficacy of their treatment and anticipated the worse in that they believed that death was inevitable. These negative cognitions seemed to diminish these women's well-being and acted to hinder their interactions with their support systems and consequently the interpretation of the care that they received. Several studies have suggested that a lack of appropriate information (Mosavel et al., 2009; Mosavel et al., 2010), cultural influences (Maree et al., 2014; Noor-Mahomed et al., 2003) as well as stigma (Mosavel et al., 2010) influence the manner in which individuals interpret illness and the attitudes that they develop towards their condition and the treatment thereof. Negative cognitions develop in response to negative influences arising from such factors, which may have fostered the fatalistic ideas reported by certain women in this study. The suffering that women associated with cervical cancer and its treatment ultimately underlie the fatalistic attitudes that developed (Maree et al., 2017; Noor-Mohammed et al, 2003), which has a negative influence on well-being.

Despite the fatalistic beliefs that were evident, and the doubt in the efficacy of the treatment that they received, women were not discouraged from attending scheduled follow up appointments and further health promoting behaviour. Mosavel et al. (2009) corroborates these findings; women persevered through treatment and continued to go for scheduled follow-up appointments despite their doubts and negative attitudes. Therefore, it is possible to postulate that the burden of these fatalistic beliefs did not extend to women neglecting their health despite believing that their efforts may be futile due to the feared inevitability of cancer being incurable.

5.7 Influential Interpersonal Relationships

Women indicated that certain individuals in their lives played a significant role in their experiences of cervical cancer. They formed part of vital support systems, and the dynamics of those relationships proved to influence women's subjective well-being.

5.7.1 The role of partners. Partners played an influential role in women's experiences during the trajectory of cervical cancer. Not only because of the actions of these partners, but also because of the perceived threat that cervical cancer had for women in terms of burden placed on their relationships or marriages. Supportive and understanding partners acted as buffers against the stress resulting from women's experiences of cervical cancer, but those who had less empathetic partners reported more stress due to threatened emotional security. This is in accordance with Maree et al.'s proposition that insufficient partner understanding of cervical cancer and women's experiences thereof influenced the perceived quality of support (2013).

Partners were mostly reported to be supportive and proactive and served as both emotional and instrumental sources of support for the women in this study. A consequence of this was that women developed a sense of worth and felt more secure in their relationships and were able to focus on their own health without fear of consequences to their relationships or marriages. Maree and Wright (2010) provided an explanation for similar behaviour observed in their study regarding health seeking behaviour of women in Tshwane, South Africa; women who perceived themselves to be worthy of care described less psychosocial limitations in their health-seeking behaviour despite the influence of submissive traditional gender roles which they may have been subjected to.

Women initially reported that they felt as if they were diseased, and that the symptoms of both the disease and the treatment thereof placed pressure on their intimate lives as they felt unable to engage in intimacy and knew that their fertility was compromised. The consequences of the disease itself, the stigma surrounding it and its treatment attributed to women fearing abandonment and the consequent loss of support (Learmonth et al., 2015). However, what was interesting to note in this study was that in almost every case women's fear of abandonment was not realised. Despite expecting to hear of partners projecting

attitudes shrouded in stigmatising ideas as reported in several other studies (Dutta et al., 2018; Learmonth et al., 2015; Maree & Wright, 2010), no woman in this study reported any instance where their partners expressed negative thoughts associated with gynaecological cancers shaped by culturally influenced masculine views.

5.7.2 The role of children. As indicated earlier in this chapter, the welfare of children weighed heavily on women. Therefore, interrupted child-rearing activities which arose due to both disease and treatment symptoms influenced the well-being of women. However, older **c**hildren were indicated to be a source of support for their mothers. They were reported to be encouraging and understanding of their mother's needs, and uplifted their mothers allowing them to focus on themselves during treatment. The active role that children play in their mother's lives implied that they had the potential to promote health-seeking behaviour in their mothers (Mosavel et al., 2006).

Mothers of older children reported that their children (specifically daughters) served as sources of information as they conveyed that which they had learnt at school relating to HPV and cervical cancer. Prevention projects which have been implemented at schools therefore appear to have succeeded in raising awareness of the disease and its prevention (Laubscher et al., 2015). Maree and Wright (2010) highlighted the importance of awareness campaigns in improving understanding of cervical cancer, with Leser and Francis (2010) furthering this sentiment to suggest that the promotion of family involvement may be beneficial in reducing the burden of this disease. The fact that daughters were often equipped to support their mothers informationally highlights this phenomenon, confirming what Mosavel et al. (2010) suggested: that the mother-daughter relationship is a potential channel for the dissemination of health-related information.

5.7.3 Women encountered in the waiting room. Women in this study indicated that the other women they met in the waiting room at the cervical cancer clinic served as a major

source of emotional support. An environment developed where information and encouragement were shared in an empathetic setting between women receiving treatment. Taylor (2015) described how individuals who endured a stressful event or experience had the potential to provide reliable informational support to others who shared a similar experience. The woman in this study organically created networks where such information could be shared. A consequence of this was that women felt supported, but also equipped to support other women who were entering into this journey after them.

The shared experience meant that women felt that they were understood and a sense of belonging and community developed for those who were receptive to it. Women described a feeling of companionship much like what was described by Carpenter et al. (2010), which they suggested buffered against the stress and anxiety associated with gynaecological cancers. The negative psychological consequences of a disease such as cervical cancer was therefore avoided to a degree (Carpenter et al., 2010), lessening the impact of negative psychosocial factors on subjective well-being as was indicated by women in this study.

5.8 Conclusion

When regarding the findings of this study an interesting phenomenon was apparent; women reported having limited knowledge about cervical cancer, yet as discussions continued a certain amount of knowledge and awareness was demonstrated. Women initially reported no knowledge of cervical cancer and never having heard of it, yet often acknowledged that it may have a sexual origin and also knowing that they were meant to go for Pap smears. Women also did not report experiencing stigmatising ideas, yet they were evident in the content of the interviews. Stigma and the attitudes of both themselves and those in their communities may have an unconscious influence on these women's conceptualisation of cervical cancer and what they are comfortable with disclosing in terms of their experience.

Furthermore, these attitudes extend to having an impact on important interpersonal relationships and perceived support that women received.

Chapter 6

Conclusion, Limitations and Recommendations

The main purpose of this study was to explore the psychosocial experiences of women during the trajectory of curative treatment for cervical cancer. In this chapter, I address the main objectives of this study and discuss whether they were realized. Following this, I discuss the limitations that I encountered and, considering what I gleaned regarding women's experiences, make recommendations for those who seek to conduct research in a similar field and those who are involved in the clinical setting where women with cervical cancer are encountered.

6.1 Conclusions

The interview schedule for this study was informed by both the research objectives and the illness intrusiveness theoretical framework in order to extrapolate information regarding women's psychosocial experiences of cervical cancer and their resultant subjective well-being. I have already discussed the findings of the interviews (see Chapter 5), but in order to address whether the main goal of this study was achieved, I am now able to offer conclusions regarding the individual research objectives.

6.1.1 Exploring the knowledge and attitudes of women regarding cervical cancer.

The first objective of this study was to explore women's knowledge and attitudes relating to cervical cancer, and how this had changed from prior to being diagnosed with the disease until the time of being interviewed. Most of the participants reported that they had limited knowledge regarding the disease, its symptoms, how it was diagnosed and treatment at the start of their journeys. Participants reported a broad knowledge about cancer in general, with all reporting that they viewed cancer as hereditary and a death sentence.

Several participants did not recognise their symptoms as warranting immediate medical attention initially. Participants reported that they often misattributed their symptoms to other conditions such as menstruation irregularities or hormonal imbalances. The

misinformation that participants encountered both from within their social networks and from medical professionals may also have contributed to them not considering cervical cancer as a possible cause of their symptoms.

It was clear that participants gained not only knowledge and understanding about the disease, but also empathy towards those who shared their journey through their experience. Effective communication with trusted healthcare providers facilitated the process of learning about cervical cancer, its prognosis and its treatment. The consequence of this gained understanding was far reaching; poor attitudes, fatalistic ideas and anxieties for the future were challenged, and women were better equipped to propagate accurate information regarding the disease which may raise awareness and also challenge the views that others have of cervical cancer.

6.1.2 Exploring psychosocial experiences associated with a cervical cancer diagnosis. Fear and denial were the typically reported responses to receiving a cervical cancer diagnosis, spurred on by a lack of knowledge and apprehension of what was to come in terms of treatment. Several women's reactions then evolved to include feelings of self-blame and shame, perhaps due to do the stigma associated with gynaecological cancers, which influenced how participants viewed themselves.

Stigma played an influential psychosocial role as it influenced how a diagnosis was conceptualised and the level of comfort that women felt in terms of sharing their diagnosis with others. Both culture and community factors influenced the stigmatic ideas that individuals both possessed and projected onto others, contributing to women's desire to conceal their diagnosis as they were unable to predict the reactions of individuals within their social networks. Misinformation, prejudiced ideas and discouragement were reported, which fostered the negative perception of the disease. As a result, women carefully selected who they shared their diagnosis with, indicating that partners and close family members were the

first (and often the only) choice as they were invested in the well-being of the women in this study and did not project stigmatising attitudes or ideas unto participants. Transparency with such individuals fostered supportive behaviour which was necessary as a buffer against the negative influence of cervical cancer on women's well-being.

6.1.3 Exploring psychosocial experiences associated with curative treatment for cervical cancer. Participants reported that they felt that their lives were disrupted; they could not participate in normal activities and interactions. As such, participants felt that their interpersonal relationships and support networks were also influenced by the disease and the treatment they underwent.

Partners played an important role in supporting women and fostered feelings of worth. The positive accounts of participants regarding partner interactions, understanding, and both instrumental and emotional support was associated with buffering against the stress and potential burden of the disease. Also, by not projecting the stigmatising ideas of cervical cancer onto women, partners may have protected participants from the impact of these community conceptions, challenging the negative feelings that participants may have had with regards to self-blame and shame.

Interactions with young children during treatment was a source of stress for participants as there was a need to protect them from worry and to maintain some sense of normalcy in daily live. Yet, older children on the other hand formed part of the social support network which buffered against the stress of undergoing treatment for such a disease.

The clinical setting where women received treatment for cervical cancer offered several psychosocial opportunities for women to interact with others. It was not only the interactions that women had with healthcare providers that proved beneficial, but also the connections that they established with other women undergoing treatment. Women in the waiting room provided companionship, emotional support and information which facilitated a

buffering affect against the negative experience which may have arisen for participants throughout treatment, empowering them to support others going through a similar experience.

6.1.4 Exploring the influence of cervical cancer on subjective well-being. Both cervical cancer symptoms and treatment effects interacted to influence women's well-being as their daily lives were disrupted. Changes to functioning were reported on multiple levels; physically, emotionally, sexually and psychosocially. As a result, participants often reported feeling isolated and distressed, which influenced their subjective well-being.

Majority of participants acknowledged that maintaining a positive attitude and outlook for the future throughout treatment an important coping strategy which protected their well-being. On the other hand, fatalistic views, doubt in the efficacy of treatment and distress were reported by those women who reported more negative cognitions. These participants also disclosed that they felt that their interactions within their support networks (with partners, community members and healthcare providers) was hindered and often a source of stress rather than upliftment, negatively influencing their subjective well-being.

6.2 Limitations

The first limitations which I encountered in this study involved participant recruitment. I used purposive sampling to recruit participants, which may have resulted in selection bias. Many participants in this study revealed positive attitudes and interactions within their social networks, which may not be a true representation of all women undergoing curative treatment for cervical cancer. Such individuals may have been more prone to commit to being interviewed than those who had more negative experiences or desired privacy. Participant recruitment proved challenging as the demographic characteristics which I included in this study (such as the younger age of participants), limited the number of woman able to partake. This accounted for the long duration of participant recruitment. The budgetary constraints, which I experienced, did not allow for the use of a translator which

further compounded this limitation as only English or Afrikaans women could be recruited. Those women who spoke a different first language to me may have had different culturally relevant experiences that could have provided novel descriptions and cognitions.

Finally, this study was only conducted at a single government health facility limiting the degree to which inferences could be made about women's experiences.

6.3 Recommendations

6.3.1 Recommendations for the research setting. Much local research has been conducted regarding breast cancer, yet little has explicitly focussed on gynaecological cancers. Due to the high prevalence of the disease despite the prevention efforts, more research needs to be dedicated to women's experiences of the disease from a psychological perspective in order to mitigate against the negative impact of cervical cancer on women's lives.

Lastly, efforts should be made to broaden the scope of research to include those participants from different cultural backgrounds who speak different African languages to better capture unique experiences. Specific themes that arose in this study could also inform future research question formation. Interactions with other women undergoing treatment, and in-depth accounts of the impact of mother-daughter communications with regards to cervical cancer and the propagation of knowledge, could be explored in terms of its supportive nature.

6.3.2 Recommendations for the clinical setting. It was apparent from the accounts of women who had undergone treatment for cervical cancer that their interactions with healthcare providers directly influenced their perceptions of their experiences of treatment. I recommend that healthcare providers be mindful of the previous information that women may have encountered and proceed accordingly. Accurate information needs to be disseminated in an appropriate manner which women are able to understand in order to minimise anxiety associated with both the disease and its treatment. As such, healthcare providers should be

mindful that each woman's experience is unique, and the amount of emotional and information support which they require will therefore differ.

Women often reported that they experienced prejudiced ideas and misinformation from the initial facilities where they sought care for their adverse symptoms. It is therefore important that information regarding cervical cancer and women's experiences thereof be extended to include clinics within communities. It is not just women in general who should be educated on cervical cancer and the prevention thereof, but also medical professionals that such women initially encounter as they play a role in how women perceive both themselves and the disease.

In conclusion, this study explored women's psychosocial experiences of curative treatment for cervical cancer and the factors that shaped their experiences. The 15 women who participated in this study revealed unique and in-depth accounts which allowed me to make several conclusions regarding their experiences. Gynaecological cancers such as cervical cancer present challenges such as a lack of knowledge about the disease, misinformation, the stigma that woman encountered and a lack of social support interacted to supress a woman's subjective well-being during their experience along with the unique adverse symptoms which they endured. However, a positive attitude, acceptance and understanding from loved ones, and effective communication with those who are more knowledgeable about the disease countered the negative cognitions and fears that women expressed. The healthcare setting and women encountered in that environment were of particular importance in mitigating against feelings of isolation and uncertainty and should thus be considered an important setting for woman to receive the support which they need to improve their perception of their experience and outlook for the future.

REFERENCES

Agudile, E. P. (2018). *The Roles of Social Support on Adolescent and Maternal Health Behaviors in Sub-Saharan Africa* (Doctoral dissertation).

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219-234.

Bless, C., Higson-Smith, C., & Sithole, S. L. (2013). *Fundamentals of social research methods: An African perspective* (5th). Cape Town, South Africa: Juta and Company Ltd.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101

CANSA. (2010). National Cancer Registry. Retrieved from https://www.cansa.org.za/files/2015/10/NCR_Final_2010_tables1.pdf

Carpenter, K. M., Fowler, J. M., Maxwell, G. L., & Andersen, B. L. (2010). Direct and buffering effects of social support among gynecologic cancer survivors. *Annals of Behavioral Medicine*, *39*(1), 79-90.

Carter, J., Stabile, C., Gunn, A., & Sonoda, Y. (2013). The physical consequences of gynecologic cancer surgery and their impact on sexual, emotional, and quality of life issues. *The Journal of Sexual Medicine*, *10*, 21-34.

Chirwa, S., Mwanahamuntu, M., Kapambwe, S., Mkumba, G., Stringer, J., Sahasrabuddhe, V., ... & Parham, G. (2010). Myths and misconceptions about cervical cancer among Zambian women: rapid assessment by peer educators. *Global Health Promotion*, *17*(2_suppl), 47-50.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310-357.

Cohen, P. A., Jhingran, A., Oaknin, A., & Denny, L. (2019). Cervical cancer. *The Lancet*, *393*(10167), 169-182.

Cooper, D., Hoffman, M., Carrara, H., Rosenberg, L., Kelly, J., Stander, I., ... & Shapiro, S. (2007). Determinants of sexual activity and its relation to cervical cancer risk among South African women. *BMC Public Health*, *7*(1), 341-348.

Cull, A., Cowie, V. J., Farquharson, D. I., Livingstone, J. R., Smart, G. E., & Elton, R. A. (1993). Early stage cervical cancer: psychosocial and sexual outcomes of treatment. *British Journal of Cancer*, *68*(6), 1216-1220.

De Abreu, C., Horsfall, H., & Learmonth, D. (2013). Adherence barriers and facilitators for cervical screening amongst currently disadvantaged women in the greater Cape Town region of South Africa: original research. *African Journal of Primary Health Care and Family Medicine*, *5*(1), 1-10.

De Groot, J. M., Mah, K., Fyles, A., Winton, S., Greenwood, S., DePetrillo, A. D., & Devins, G. M. (2005). The psychosocial impact of cervical cancer among affected women and their partners. *International Journal of Gynecological Cancer*, *15*(5), 918-925.

De Kubber, M. M., Peters, A. A. W., & Soeters, R. P. (2011). Investigating cervical cancer awareness: perceptions of the Female Cancer Programme in Mdantsane, South Africa: original research. *Southern African Journal of Gynaecological Oncology*, *3*(2), 70-72.

Delany-Moretlwe, S., Kelley, K. F., James, S., Scorgie, F., Subedar, H., Dlamini, N. R., ... & Rees, H. (2018). Human papillomavirus vaccine introduction in South Africa: implementation lessons from an evaluation of the national school-based vaccination campaign. *Global Health: Science and Practice*, *6*(3), 425-438.

Denny, L. (2010). Cervical cancer in South Africa: an overview of current status and prevention strategies. *Cont Med Ed*, *28*(2), 70-73.

Deverell, A., & Ross, E. (2004). *Psychosocial approaches to health, illness and disability. A reader for health care professionals*. Pretoria: Van Schaik Publishers.

Devins, G. M. (2010). Using the illness intrusiveness ratings scale to understand health-related quality of life in chronic disease. *Journal of Psychosomatic Research*, *68*(6), 591-602.

Devins, G. M., Bezjak, A., Mah, K., Loblaw, D. A., & Gotowiec, A. P. (2006). Context moderates illness-induced lifestyle disruptions across life domains: a test of the illness intrusiveness theoretical framework in six common cancers. *Psycho-Oncology*, *15*(3), 221-233.

Devins, G. M., Dion, R., Pelletier, L. G., Shapiro, C. M., Abbey, S., Raiz, L. R., ... & Edworthy, S. M. (2001). Structure of lifestyle disruptions in chronic disease: a confirmatory factor analysis of the Illness Intrusiveness Ratings Scale. *Medical Care*, *39*(10), 1097-1104.

Drolet, M., Bénard, É., Pérez, N., Brisson, M., Ali, H., Boily, M. C., ... & Checchi, M. (2019). Population-level impact and herd effects following the introduction of human papillomavirus vaccination programmes: updated systematic review and meta-analysis. *The Lancet*, *394*(10197), 497-509.

Du Toit, G. C., & Kidd, M. (2013). Contextual quality of life of HIV-positive patients with cervical carcinoma at Tygerberg Hospital: original research. *Southern African Journal of Gynaecological Oncology*, *5*(2), 41-46.

Dutta, T., Haderxhanaj, L., Agley, J., Jayawardene, W., & Meyerson, B. (2018). Peer Reviewed: Association Between Individual and Intimate Partner Factors and Cervical Cancer Screening in Kenya. *Preventing Chronic Disease*, *15*(157), 1-9.

Francis, S. A., Battle-Fisher, M., Liverpool, J., Hipple, L., Mosavel, M., Soogun, S., & Mofammere, N. (2011). A qualitative analysis of South African women's knowledge, attitudes, and beliefs about HPV and cervical cancer prevention, vaccine awareness

and acceptance, and maternal-child communication about sexual health. *Vaccine*, *29*(47), 8760-8765.

Gülaçtı, F. (2010). The effect of perceived social support on subjective well-being. *Procedia-Social and Behavioral Sciences*, *2*(2), 3844-3849.

Hoque, E., & Hoque, M. (2009). Knowledge of and attitude towards cervical cancer among female university students in South Africa. *Southern African Journal of Epidemiology and Infection*, *24*(1), 21-24.

Holland, J. C. (2002). History of psycho-oncology: overcoming attitudinal and conceptual barriers. *Psychosomatic Medicine*, *64*(2), 206-221.

Jansen van Rensburg, J. J. M., Maree, J. E., & Casteleijn, D. (2017). An investigation into the quality of life of cancer patients in South Africa. *Asia-Pacific Journal of Oncology Nursing*, *4*(4), 336-341.

Kebede, W., & Kebede, K. (2017). Psychosocial experiences and needs of women diagnosed with cervical cancer in Ethiopia. *International Social Work*, *60*(6), 1632-1646.

Laubscher, N., Botha, M. H., Van der Merwe, F. H., Dreyer, G., Snyman, L. C., Visser, C., ... & Lindeque, B. G. (2015). The Vaccine and Cervical Cancer Screen project: experiences from a primary school-based vaccine implementation studying Gauteng and the Western Cape, South Africa. *Professional Nursing Today*, *19*(2), 28-31.

Learmonth, D., Jansen van Vuuren, A., & De Abreu, C. (2015). The influence of gender roles and traditional healing on cervical screening adherence amongst women in a Cape Town peri-urban settlement. *South African Family Practice*, *57*(2), 62-63.

Leser, K. A., & Francis, S. A. (2014). Mother-child communication about sexual health, HPV and cervical cancer among antenatal clinic attendees in Johannesburg, South Africa. *African Journal of Reproductive Health*, *18*(1), 123-126.

Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation*, *1986*(30), 73-84.

Mah, K., Bezjak, A., Loblaw, D. A., Gotowiec, A., & Devins, G. M. (2011). Do ongoing lifestyle disruptions differ across cancer types after the conclusion of cancer treatment?. *Journal of Cancer Survivorship*, *5*(1), 18-26.

Maree, J. E., Cur, d., & Kaila, I. (2014). Zambian women's experiences and understanding of cervical cancer: A qualitative study. *International Journal of Gynecological Cancer*, *24*(6), 1065-1071.

Maree, J. E., Mosalo, A., & Wright, S. C. D. (2013). 'It depends on how the relationship was before you became ill': Black South African women's experiences of life partner support through the trajectory of cervical cancer. *European Journal of Cancer Care*, *22*(4), 459-467.

Maree, J. E., & Wright, S. C. (2010). How would early detection be possible? An enquiry into cancer related knowledge, understanding and health seeking behaviour of urban black women in Tshwane, South Africa. *European Journal of Oncology Nursing*, *14*(3), 190-196.

Momberg, M., Botha, M. H., Van der Merwe, F. H., & Moodley, J. (2017). Women's experiences with cervical cancer screening in a colposcopy referral clinic in Cape Town, South Africa: a qualitative analysis. *BMJ Open*, *7*(2), 1-6.

Mosavel, M., Simon, C., & Ahmed, R. (2010). Cancer perceptions of South African mothers and daughters: Implications for health promotion programs. *Health Care for Women International*, *31*(9), 784-800.

Mosavel, M., Simon, C., Oakar, C., & Meyer, S. (2009). Cervical cancer attitudes and beliefs—A Cape Town community responds on World Cancer Day. *Journal of Cancer Education*, *24*(2), 114-119.

Mosavel, M., Simon, C., & Van Stade, D. (2006). The mother–daughter relationship: What is its potential as a locus for health promotion?. *Health Care for Women International*, *27*(7), 646-664.

National Department of Health. (2017). Cervical Cancer Prevention and Control Policy. Retrieved from http://www.health.gov.za/index.php/2014-08-15-12-53-24?download=1393:cervical-cancer-policy-pdf

Ngcobo, N. J., Burnett, R. J., Cooper, S., & Wiysonge, C. S. (2019). Human papillomavirus vaccination acceptance and hesitancy in South Africa: Research and policy agenda. *South African Medical Journal*, *109*(1), 13-15.

Noor-Mahomed, S. B., Schlebusch, L., & Bosch, B. A. (2003). Suicidal behavior in patients diagnosed with cancer of the cervix. *Crisis: The Journal of Crisis Intervention and Suicide Prevention*, *24*(4), 168-172.

Ntinga, S. N., & Maree, J. E. (2015). Living with the late effects of cervical cancer treatment: a descriptive qualitative study at an academic hospital in Gauteng. *Southern African Journal of Gynaecological Oncology*, *7*(1), 21-26.

Pillay, A. L. (2002). Rural and urban South African women's awareness of cancers of the breast and cervix. *Ethnicity and Health*, *7*(2), 103-114.

Sabulei, C., & Maree, J. E. (2019). An exploration into the quality of life of women treated for cervical cancer. *Curationis*, *42*(1), 1-9.

Singh, K. (2007*). Quantitative Social Research Methods.* Thousand Oaks, CA: SAGE Publications.

Stewart, T. S., Moodley, J., & Walter, F. M. (2018). Population risk factors for late-stage presentation of cervical cancer in sub-Saharan Africa. *Cancer Epidemiology*, *53*, 81-92.

Suter, W. N. (2012). *Introduction to educational research: A critical thinking approach* (2nd). Thousand Oaks, California: SAGE publications, Inc.

Tathiah, N., Moodley, I., Denny, L., Moodley, J., & Jassat, W. (2014). Cervical cancer in South Africa: challenges and opportunities. *South Africa Health Review*, *2013*, 117-126.

Taylor, S. E. (2015). *Health psychology* (9th). McGraw-Hill Education.

Western Cape Government. (2020) Cervical Cancer. Retrieved from https://www.westerncape.gov.za/general-publication/cervical-cancer

World Health Organization. (2014). GLOBOCAN 2012: Estimated cancer incidence, prevalence and mortality worldwide in 2012. Retrieved from http://globocan.iarc.fr/Default.aspx

World Health Organization. (2019a). GLOBOCAN 2018: Cervix Uteri. Retrieved from https://gco.iarc.fr/today/data/factsheets/cancers/23-Cervix-uteri-fact-sheet.pdf

World Health Organization. (2019b). GLOBOCAN 2018: South Africa. Retrieved from https://gco.iarc.fr/today/data/factsheets/populations/710-south-africa-fact-sheets.pdf

APPENDICES

Appendix A

Flyer (Recruitment Materials)

PSYCHOSOCIAL EXPERIENCES OF CERVICAL CANCER

Research Study

You are invited to participate in a study which aims to explore your experience of cervical cancer.

This research aims to explore women's psychological and social experiences associated with diagnosis and treatment of cervical cancer at the Division of Medical Imaging and Clinical Oncology at Tygerberg Hospital.

Individuals who wish to participate need to be between the ages of 18 and 50, and must have concluded treatment for cervical cancer at Tygerberg Hospital no longer than 18 months ago.

You will be asked to participate in an interview. All participants will receive a token of appreciation as well as a contribution towards travel costs to this interview.

If you have any questions with regards to this study and/or are interested in participating please speak to the nurse or receptionist where you received this flyer, or feel free to contact the researcher whose details are provided below.

This study is being conducted under the auspices of the Department of Psychology at Stellenbosch University. Ethical clearance was provided by Stellenbosch University's Health Research Ethics Committee and permission to conduct the study was granted by Western Cape Department of Health.

Researcher	Supervisor	Co-supervisor
Ms. R Williams	Dr. R Roomaney	Prof. H Simonds
robcwill87@gmail.com	rizwanaroomaney@sun.ac.za	hsimonds@sun.ac.za

Appendix B

Participant Information Leaflet and Consent Form (English Version)

Title of the Research Project:

A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

Reference Number:

Principle Investigator: Robyn Carol Williams

Address: 328 Helderberg Village
Bakkerskloof road
Somerset West
7130

Contact Number: 072 456 3539

Supervisor: Dr Rizwana Roomaney

Address: Department of Psychology
Stellenbosch University
Room 2019; RW Wilcocks Building; Ryneveld Street; Stellenbosch; 7600

Contact Number: 021 808 3973

Co-supervisor: Prof Hannah Simonds

Address: Division of Radiation Oncology
Department Medical Imaging and Clinical Oncology
Stellenbosch University and Tygerberg Hospital
Gene Louw Building; Francie van Zijl Drive; Tygerberg; Cape Town; 7500

Contact Number: 021 938 4727

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study will be conducted at Tygerberg Hospital's Radiation Oncology Unit where between 25 and 30 participants will be recruited to take part.
- This project aims to explore women's experience of cervical cancer from before they were diagnosed with the disease until treatment ends. We want to discuss your knowledge about cervical cancer and attitudes towards women who had the disease before you were diagnosed yourself, and whether these ideas and attitudes have changed during your treatment because of your personal experiences. It is important to discuss how you feel cervical cancer treatment has affected your well-being and views about your future. Awareness of women's experiences and views about cervical cancer treatment allows health care providers to better create a treatment plan which tends to the specific needs of cervical cancer patients, both physically and psychologically, in order to improve patient's well-being both during and after treatment.
- Once you choose to participate in the study, we will arrange to meet at the Radiation Oncology Unit at Tygerberg Hospital at a date and time that is convenient for you. We will meet in a private room in the unit to make sure that your confidentiality is protected and to make you feel more comfortable. At this point you will be required to sign this document to give consent before our interview can take place. The interview will last for approximately one hour during which time we will discuss your experiences of cervical cancer treatment. You are free to stop the interview at any point if you feel uncomfortable. There will be no negative consequences for you should you choose to leave the study. You will be given a R100 contribution towards your transportation costs to the interview as well as a R50 Shoprite voucher as a token of appreciation. This is to ensure that you do not have any personal costs due to the study. Should you wish to receive information about the study after it is finished this will be noted and the information will be communicated to you.

Why have you been invited to participate?

- You have been invited to participate in this study because you have received treatment for cervical cancer within the last 6 months at Tygerberg Hospital's Radiation Oncology Unit. This means that you have information about your experiences which are valuable to us learning about how cervical cancer and its treatment influences women's lives. We are only inviting women who are between the ages of 18 and 50, and who can both speak and understand either English or Afrikaans.

What will your responsibilities be?

- It is your responsibility to consider whether you are able to commit to an interview and participating in the study despite other responsibilities such as work or family commitments. It is also your responsibility to get yourself to and from the interview on the appropriate date.

Will you benefit from taking part in this research?

- There are no expected personal benefits for you in taking part in this study other than benefits that come from speaking about your experiences. Despite there being no personal incentives for you to participate in the study, the information gathered about women's experiences during treatment may help healthcare providers to be more considerate of women's needs in the future to improve their psychological and physical well-being during and after treatment.

Are there in risks involved in your taking part in this research?

- There are no expected risks involved in you taking part in this study.

Who will have access to your medical records?

- Any information that you share with me will be protected and treated as confidential. You will remain anonymous during the study and this will also be respected when the results of the study are written up in my Master's Thesis or any subsequent publications. The only people who will have access to your information will be myself as the primary investigator (Robyn Williams), my supervisors (Dr Rizwana Roomaney and Prof Hannah Simonds).

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

As participant there is no risk of incurring physical injury during this study as no intervention is proposed. Should you experience any emotional distress during the interview process, you will be referred to the available counselling services at the Welgevallen Community Psychology Clinic (Welgevallen House, Suidwal Street, Stellenbosch),

Phone: 021 808 2696 **Email:** WCPC@sun.ac.za

or at the Hope House Counselling Centre (6 Lang Street, Kuils River)

Phone: 021 903 0521 **Email:** info@hopehouse.org.za

Participants will not incur any costs should they be referred for counselling.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You can contact Robyn Williams at 072 456 3539 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the primary investigator, or you can contact the study supervisors:
  Dr Roomaney (021 808 3973)
  Prof Simonds (021 938 4727)
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ……..……. agree to take part in a research study entitled A Qualitative Study Exploring Women's Psychosocial Experiences of Curative Treatment of Cervical Cancer and Whether it Influences Subjective Well-being.
I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2018.

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2018.

....

Signature of investigator **Signature of witness**

Appendix C

Demographic Information Form

Exploring women's psychosocial experiences of cervical cancer.

DEMOGRAPHIC INFORMATION

Please answer the questions below:

1. LAST NAME

2. FIRST NAME

3. AGE

4. DATE OF BIRTH: _____ _____ _____

Day Month Year

PLEASE INDICATE THE FOLLOWING ANSWERS BY MAKING AN (X) IN THE APPROPRIATE BOX.

5. RACE:

□ AFRICAN □ COLOURED

□ WHITE □ INDIAN

□ OTHER (Please state: _____.

6. MARITAL STATUS:

□ Single □ Widowed □ Separated □ Divorced

□ Married/ living together

7. LIVING SITUATION:

□ Live alone □ Live with other adults(s), no children

□ Live with other adults and children □ Live with children

□ Live in an institution or retirement home

8. WHAT IS THE HIGHEST EDUCATION LEVEL YOU HAVE COMPLETED?

□ No formal education

□ Completed primary school

□ Attended high school but did not complete matric

□ Completed matric

□ Attended university, college or Technikon but did not graduate

□ Graduated from university, college or Technikon

9. WHAT IS YOUR CURRENT WORK SITUATION?

□ Employed full time □ Employed part time □ Student

□ Unemployment □ Disabled □ Homemaker

□ Retired

10. WHICH OF THE FOLLOWING BEST DESCRIBES YOUR APPROXIMATE MONTHLY FAMILY INCOME FROM ALL SOURCES, BEFORE TAXES?

□ Less than R2500 □ R2 501 - R5 000 □ R5 001-R10 000

□ R10 001 – R15 000 □ R15 001 and above □ Don't know

11. WHAT IS YOUR FIRST LANGUAGE? _____

12. WHICH OTHER LANGUAGES DO YOU SPEAK? _____

MEDICAL INFORMATION

Date of diagnosis: _____

Stage of cancer at diagnosis: _____

Treatment undergone:

_____-

_____

_____

_____

_____

Appendix D

Interview Schedule

1. Please describe what you knew about cervical cancer before you were diagnosed.

   Prompt: what did you think of other women with cervical cancer? When was the first time that you heard about cervical cancer?

   [Beskryf asseblief wat u van servikale kanker geweet het voordat u gediagnoseer is.

   Prompt: Wat het jy van ander vroue met servikale kanker gedink? Wanneer was die eerste keer wat jy van servikale kanker gehoor het?]

2. What motivated you to see the clinic/doctor for a Pap smear or to seek medical attention?

   Prompt: was it a routine Pap smear or were you experiencing symptoms? Can you describe your symptoms? Was there anyone who advised you to see the doctor or visit the clinic?

   [Wat het jou gemotiveer om die kliniek/dokter te besoek vir 'n Pap-smeer of om mediese aandag te kry?

   Prompt: was dit 'n roetine Pap-smeer of het jy simptome gehad? Kan jy jou simptome beskryf? Was daar iemand wat jou aangemoedig om die dokter of die kliniek te besoek?]

3. Can you describe what you were thinking when you were diagnosed?

   Prompt: how did you feel about telling people about your diagnosis? How did your family react to finding out you have cervical cancer?

   [Kan jy beskryf wat jy gedink het toe jy gediagnoseer is?

   Prompt: hoe het jy gevoel om mense te vertel van jou diagnose? Hoe het jou familie gereageer om uit te vind dat jy servikale kanker het?]

4. Please describe the treatment you received.

   Prompt: What you did you think about the treatment?

[Beskryf asseblief die behandeling wat u ontvang het.

Prompt: Wat het jy van die behandeling gedink?]

5. How did you feel during treatment?

   Prompt: did treatment affect other areas of your life such as your relationships at home or at work?

   [Hoe het jy tydens die behandeling gevoel?

   Prompt: het behandeling ander dele van jou lewe beïnvloed, soos jou verhoudings by die huis of by die werk?]

6. Were you able to get help during treatment? What sort of support did you receive while on treatment?

   [Was u in staat om hulp tydens behandeling te kry? Watter soort ondersteuning het u tydens behandeling ontvang?]

7. Was your husband/partner supportive? Did you have help with household chores and looking after the children? How did your social network treat you during treatment? What support did you get from your healthcare providers? What did you do to cope?

   [Was u man ondersteunend? Het u hulp gehad met huishoudelike take en on na die kinders te kyk? Hoe het jou sosiale netwerk jou behandel tydens behandeling? Watter ondersteuning het u van u gesondheid sorgverskaffers gekry? Wat het jy gedoen om te dit te hanteer?]

8. What would have made this experience better for you?

   Prompt: what could your family and friends have done? Is there anything your social network could do to make treatment easier for you? What about your healthcare providers?

   [Wat sou hierdie ervaring vir jou beter gemaak het?

Prompt: wat kon jou familie en vriende gedoen het? Is daar enigiets jou sosiale netwerk kon doen om behandeling vir jou makliker te maak? Wat van jou gesondheid sorgverskaffers?]

9. If you had to give advice to a woman who is about to start treatment for cervical cancer what would it be?

   [As jy advies moes gee aan 'n vrou wat behandeling vir servikale kanker gaan begin, wat sou dit wees?]

10. Finally, is there anything that you would like to add to our discussion about your experience of cervical cancer?

    [Is daar enigiets wat u graag wil byvoeg by ons bespreking oor u ervaring van servikale kanker?]

Appendix E

Health Research Ethics Committee Approval Letter

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Health Research Ethics Committee (HREC)

Approval Notice

New Application

Ethics Reference #:1674

Title: A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

HREC Reference # S17/10/202

Dear Ms R Williams

The **New Application** received on 11/10/2017 13:50 was reviewed by members of **Health Research Ethics Committee** via **expedited** review procedures on 16/01/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **16-Jan-2018 – 15-Jan-2019**

Please remember to use your protocol number Project Id on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: https://applyethics.sun.ac.za/Project/Index/1834 and the application should be submitted to the Committee before the year has expired. Please see Forms and Instructions on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website Links Application Form Direct Link

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Franklin Weber

HREC Coordinator

Health Research Ethics Committee 1 (HREC 1)

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles, Structures and Processes 2015 (Department of Health).

Appendix F

Western Cape Department of Health Approval Letter

Western Cape Government
Health

TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG Marinus**
TELEPHONE:**021 938 5752**

Ethics Reference: **S17/10/202**

TITLE: A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

Dear Ms R Williams

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

DR GG MARINUS
MANAGER: MEDICAL SERVICES

DR D ERASMUS
CHIEF EXECUTIVE OFFICER
Date: 20 February 2018

Administration Building, Francie van Zijl Avenue, Parow, 7500 Private Bag X3, Tygerberg, 7505
tel: +27 21 938-6267 fax: +27 21 938-4890 www.capegateway.gov.za

TYGERBERG HOSPITAL

Ethics Reference: **S17/10/202**

TITLE: A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

BY 

An authorized representative of Tygerberg Hospital

NAME Dr DS Erasmus

TITLE CEO

DATE 20 February 2018

Appendix G

Project Extension Letter of Permission

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Health Research Ethics Committee (HREC)

Approval Notice

New Application

05/02/2019

Project ID :1674

HREC Reference # S17/10/202

Title: A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

Dear Ms Robyn Williams ,

Your request for extension/annual renewal of ethics approval dated 11/01/2019 11:04 refers.

The Health Research Ethics Committee reviewed and approved the following annual progress report you submitted through an expedited review process:-

Progress Report 06-Mar-2018 to 13-Dec-2018

The approval of this project is extended for a further year.

Approval date: 16 January 2019
Expiry date: 15 January 2020

Please remember to use your project ID (1674)on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/1674

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Melody Shass ,

Coordinator,

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix H

Amendments and Additions to Research Protocol Letter of Permission

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Amendment Approval Letter

12/02/2019

Project Reference #: 1674

Ethics Reference #: S17/10/202

Title: A qualitative study exploring women's psychosocial experiences of curative treatment of cervical cancer and their subjective well-being.

Dear Ms Robyn Williams ,

Your amendment request # 1 dated 13/12/2018 refers,

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved:-

1. To extend study period until the end of 2019 to allow for further participant recruitment and data capturing.
2. To add a simple demographic form to the protocol to accurately and consistently record demographic details of participants who give consent.
3. Revise the research protocol:-

   (a) To relax the inclusion criteria for participants to include women up to 18 months post-treatment (instead of up to 6 months).
   (b) To be permitted to interview women in venues that are more convenient for them such as their own homes or a private office in the Department of Psychology.
   (c) To interview women at a different venue at Tygerberg Hospital should participants only be available after 16h00 in the afternoons during the week or during weekends.

Based on the above the following amended documents have been reviewed and approved:-

1. Research protocol version 2, dated 13 December, 2018
2. Information leaflet version 2, dated 29 November, 2018
3. Demographic information form version 1, dated 29 November, 2018

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your Project ID [1674] and ethics reference number S17/10/202 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Melody Shana,

Coordinator,

HREC1.

National Health Research Ethics Council (NHREC) Registration Numbers: REC-130406-012 for HREC1 and REC-230206-010 for HREC2

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0006240 for HREC1

Institutional Review Board (IRB) Number: IRB0006239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles, Structures and Processes 2015 (Department of Health)